

SOCIAL ADJUSTMENT IN CHILDREN WITH CANCER

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# TABLE OF CONTENTS

	<u>page</u>
ACKNOWLEDGEMENTS .....	ii
LIST OF TABLES .....	v
ABSTRACT .....	vi
INTRODUCTION .....	1
Overview of Pediatric Cancer .....	4
Social Development .....	20
Social Competence .....	26
Social Functioning .....	35
Research on Psychosocial Adjustment to Cancer .....	46
Rationale and Hypotheses .....	55
METHOD .....	61
Participants .....	61
Measures .....	62
Procedure .....	77
RESULTS .....	84
Demographic and Cancer Information .....	84
Measure Information .....	96
Comparisons Between the Cancer and Control Groups ..	103
Comparisons Within the Cancer Group .....	108
DISCUSSION .....	113
APPENDIX A DEMOGRAPHIC QUESTIONNAIRE .....	129
APPENDIX B CANCER QUESTIONNAIRE .....	132

	<u>page</u>
APPENDIX C INFORMED CONSENT FOR NON-CNS CANCER PARTICIPANTS .....	134
APPENDIX D INFORMED CONSENT FOR CNS CANCER PARTICIPANTS .....	142
APPENDIX E INFORMED CONSENT FOR CONTROL PARTICIPANTS ..	150
REFERENCES .....	153
BIOGRAPHICAL SKETCH .....	167

# LIST OF TABLES

<u>Table</u>	<u>page</u>
1. Theories of Social Development .....	25
2. Theories of Social Competence .....	34
3. Measure Information .....	63
4. Demographic Information .....	88
5. Categorical Disease Variables .....	92
6. Non-Categorical Disease Variables .....	95
7. Diagnosis Information .....	97
8. Descriptive Statistics .....	99
9. SAICA-CBCL Scale and Subscale Comparisons ...	102

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As the prognosis and survival rate for most pediatric cancers have improved, studying the social adjustment of children with cancer has taken on greater importance given that social functioning has implications for both short-term and long-term adjustment. Studies that can identify variables associated with social maladjustment among pediatric oncology patients would be useful since this information could be used to target those children in most need of social intervention. The main focus of the present research was to examine the relationships among individual characteristics, disease characteristics, psychological variables,

and children's social functioning. Healthy children were included as a comparison group since this made it possible to examine whether pediatric cancer patients differed from healthy youth in background characteristics as well as psychosocial variables.

Study participants were 175 children between 5 and 12 years of age. Information was gathered from parents, medical personnel, and children via their responses to questionnaires. Statistical analyses revealed that children with cancer had worse social adjustment, lower levels of friend support, and higher levels of social anxiety when contrasted with healthy children. For all children, higher levels of social support and lower levels of social anxiety were associated with better social adjustment. Within the Cancer Group, poor adjustment was associated with having limited friend support, a high level of social anxiety, greater constraints in socialization, and being on treatment or having residual disease/treatment effects. Having a brain tumor was also related to lower social functioning, but to a lesser degree. The implications of the various findings with regard to social intervention programs for pediatric oncology patients are discussed.

## INTRODUCTION

Although childhood cancer is relatively rare when compared to adult cancer, cancer is still a leading cause of death in pediatric populations (Miller, Young, & Novakovic, 1994; Nemes & Donahue, 1994; Stehbens, 1988). Fortunately, medical advances since the 1960s such as improvements in medical treatments and better technology, have led pediatric cancer to become best conceptualized as a life-threatening chronic illness rather than an acute fatal disease (Baum & Baum, 1989; Eiser, 1998; Michael & Copeland, 1987; Miller et al. 1994; Powers, Vannatta, Noll, Cool, & Stehbens, 1995; Rowland, 1989; Stehbens, 1988). As the prognosis and survival rates for most childhood cancers have improved, addressing social functioning in pediatric oncology patients have taken on greater importance given that social functioning has implications for both short-term and long-term psychological adjustment (LaGreca, 1990; Rowland, 1989; Siegel, 1990; Spirito, DeLawyer, & Stark, 1991).



Research has consistently revealed that the quality of peer relationships during childhood plays a vital role in adjustment throughout the life-span (Coie & Cillessen, 1993; LaGreca, 1990; Parker & Asher, 1987; Spirito, et al. 1991). For instance, when compared to individuals with a history of average peer functioning, people with a history of poor peer relations have been found to demonstrate elevated levels of numerous difficulties in adolescence and adulthood. These troublesome outcomes include higher than average rates of externalizing and internalizing behavior problems, school dropout, and criminality (Coie & Cillessen, 1993; Parker & Asher, 1987). Congruent with the findings from studies of the general population, there are some indications from the chronic disease literature that children with good peer relations have better illness/disease adaptation than those with poor peer relations (LaGreca, 1990).

While most research to date, which will be discussed in considerably greater detail later, suggests that the majority of pediatric cancer survivors have approximately normal levels of social functioning, there is some evidence that a significant minority of children with cancer do experience

psychological difficulties and could benefit from intervention (Kazak, 1994; Kazak and Meadows, 1989; Kupst, 1994; Kupst, et al. 1995; Noll, Bukowski, Rogosch, LeRoy, & Kulkarni, 1990; Noll, Ris, Davies, Bukowski, & Koontz 1992; Noll, Bukowski, Davies, Koontz, & Kulkarni, 1993; Spirito et al. 1990). LaGreca (1990) asserts that diseases which are most likely to have an adverse effect on children's social functioning are those illnesses that restrict physical activities, disturb normal daily routines, affect physical appearance, and necessitate life-style changes. Since cancer appears to satisfy all of LaGreca's (1990) criteria for a disease that has a strong potential for disrupting children's peer relations, studying the social functioning of pediatric oncology patients seems to be a worthwhile endeavor. As noted by LaGreca (1990) and Kupst et al. (1995), investigations that can help identify variables associated with an increased probability of social maladjustment among children with cancer would be particularly useful. Information gathered from such studies could then be utilized to target the children who are in the greatest need of social interventions.

## Overview of Pediatric Cancer

### Types and Symptoms of Childhood Cancer

The cancers of childhood are highly diverse. Leukemias or cancers of the blood are the most common malignancies in childhood (Miller et al. 1994; Powers et al. 1995; Stehbens, 1988). Usually of unknown etiology, leukemias originate in the child's bone marrow, which starts to produce malignant cells and results in an increased white blood cell count (Stehbens, 1988). Typical symptoms of the majority of leukemias are paleness, fatigue, fever, a proneness to infection, and easy bruising and bleeding (Meadows, Belasco, & Sinniah, 1992; Stehbens, 1988).

Comprising 30 to 40% of all pediatric cancers, acute lymphocytic/lymphoblastic leukemias or ALL are a group of 7 diseases that represent the most frequent type of leukemia in children (Miller et al. 1994; Stehbens, 1988). The incidence of ALL peaks between 3 and 5 years of age (Meadows et al. 1992). On the other hand, approximately 20% of childhood leukemias are acute non-lymphocytic or acute myeloid cancers (i.e., ANLL) (Belasco, Sinniah, & Meadows, 1992). When compared to ALL, children with ANLL tend to be older

and have a greater probability of presenting with chloromas (i.e., a solid leukemic mass with surface greenish color in a freshly cut specimen) (Belasco, et al. 1992). ANNL is also more likely than ALL to develop as a secondary cancer (Belasco, et al. 1992). Acute myeloblastic, acute monocytic, and acute megakaryoblastic are among the seven subtypes of ANNL (Belasco, et al. 1992).

Relatively rare in childhood, chronic myeloid leukemias (CML) make up 2 to 5% of pediatric leukemias. CML involves the presence of the Philadelphia chromosome, which indicates a translocation of the long arms of chromosomes 9 and 22 (Lange, 1992). Frequently having an insidious symptom onset, CML is often characterized by malaise, weight loss, and splenomegaly (Lange, 1992). Most children with CML develop a blast crisis that requires intervention (Lange, 1992).

Children can also have preleukemic states that often develop into overt leukemia (Lange, 1992). These preleukemic states typically have symptoms similar to those of full-blown leukemias (Lange, 1992). Interestingly, a preleukemic phase is frequently seen in disorders associated with a high

risk of developing leukemia, such as neurofibromatosis, Down's syndrome, and Fanconi's anemia (Lange, 1992).

Approximately 20% of pediatric tumors are brain cancers, the most common solid tumors in children (Powers et al. 1995; Stehbens, 1988). Often fatal, brain tumors are classified according to their main atypical cell type, with their symptoms depending largely upon their location (Cohen & Packer, 1992; Stehbens, 1988). Brain tumors are often classed in accordance with their location relative the tentorium or base of the brain (Baron et al. 1995). Subtentorial tumors of various pathologies are characterized by symptoms of elevated intracranial pressure, such as headache, irritability, nausea, and vomiting (Stehbens, 1988). Types of subtentorial tumors include medulloblastoma and brain stem gliomas, which both have very poor long term survival rates (i.e., typically under 20% at 5 years post diagnosis) (Cohen & Packer, 1992; Shiminski-Maher & Shields, 1995). Most frequently occurring in the subtentorial region, ependymomas typically have a better prognosis than the aforementioned tumors (Cohen & Packer, 1992; Shiminski-Maher & Shields, 1995). Visual changes, endocrine pathologies,

and hydrocephalous characterize midline tumors. The most common kind of midline tumors, craniopharyngiomas have a good prognosis if they are totally resected (Cohen & Packer, 1992). Unfortunately, resection of these tumors can sometimes result in very serious neurological and endocrine complications (Cohen & Parker, 1992; Shiminski-Maher & Shields, 1995). Lastly, symptoms of various supratentorial tumors can include hemiparesis, visual field problems, seizures, and endocrine problems (Shiminski-Maher & Shields, 1995; Stehbens, 1988). Roughly 80% of supratentorial tumors, such as most astrocytomas, are benign. However, anaplastic astrocytomas and glioblastomas are malignant types which are highly virulent (Shiminski-Maher & Shields, 1995).

Arising from neural crest cells and first occurring in the abdomen, chest, cervical, and pelvic areas, neuroblastoma is a cancer of the sympathetic nervous system that can metastasize to the brain (Miller et al. 1994; Nemes & Donahue, 1994; Stehbens, 1988). Individuals with neuroblastoma often exhibit flu-like symptoms (Nemes & Donahue, 1994). Wilm's tumor and hepatoblastoma are the most common renal and liver tumors effecting children, respectively (Nemes &

Donahue, 1994; Stehbens, 1988). Children with kidney and liver tumors most frequently present with either increased abdominal girth or a mass in the abdominal region (Nemes & Donahue, 1994; Stehbens, 1988). Hodgkins Disease and other lymphomas, which are typically characterized by an enlargement of the lymph nodes, are also relatively common cancers in childhood (Stehbens, 1988). A soft tissue cancer often seen in childhood is rhabdomyosarcoma, which usually occurs in the head and neck area in the form of a mass (Stehbens, 1988). Lastly, the bone cancers most frequently seen in children are Osteogenic sarcoma and Ewings sarcoma (Miller et al. 1994; Stehbens, 1988). Pain and a growth at the tumor site are some of the common symptoms of bone tumors (Stehbens, 1988).

#### Detection and Treatment of Childhood Cancer

Unlike many adult cancers, survival rates from the majority of childhood cancers are not significantly increased by early detection (Stehbens, 1998). However, many pediatric malignancies are more amenable to treatment than adult malignancies (Miller et al. 1994). The type of cancer and the child's likelihood of surviving the illness are related,

in part, to the child's age at disease onset (Miller et al. 1994; Nemes & Donahue, 1994; Stehbens, 1988). Most pediatric malignancies are first diagnosed between birth and 4 years of age (Stehbens, 1988). The most common types of cancers among young children are acute lymphoblastic leukemia (ALL), neuroblastoma, Wilm's tumor, and hepatoblastoma (Miller et al. 1994; Stehbens, 1988). After age 5, the rates of bone cancers and lymphomas gradually increase such that by age 20, the most frequent kinds of cancer are carcinomas rather than the sarcomas that predominate in childhood (Miller et al. 1994; Stehbens, 1988). Prognosis is usually worse if individuals are diagnosed with a cancer that is atypical for their age group or if the disease has reoccurred (Cincotta, 1993; Nemes & Donahue, 1994; Stehbens, 1988).

The majority of pediatric cancers are treated by combining chemotherapy with radiation, surgery, and, in more extreme cases, bone marrow transplantation or BMT (Stehbens, 1988). Both chemotherapy and radiotherapy are designed to kill the most rapidly metabolizing cells in the body, which include, but is not limited to, cancer cells (Stehbens,



1988). Chemotherapy involves the administration of drugs aimed at destroying or, at a minimum, controlling the reproduction of malignant cells (Baron, Fennell, & Voeller, 1995; Stehbens, 1988). Radiotherapy consists of directing radiation to diseased areas and to regions in the body where the cancer has a propensity to metastasize (Baron et al. 1995). Surgery entails the removal of the tumor/diseased-stricken region (Baron et al. 1995; Stehbens, 1988). Unfortunately, many of these interventions have aversive components (i.e., frequent injections) and both short-term and long-term side effects (i.e., nausea and changes in physical appearance) that can be often more painful and distressing than the disease itself (Ellis & Spanos, 1994; Jay, 1988; Zelter, 1994).

Typically limited to treatment for highly malignant or recurrent cancers, BMT most often involves exposure to very high doses of chemotherapy and radiation (Stehbens, 1988). Resulting in destruction of the immune system, these treatments would be fatal if new bone marrow was not infused into and accepted by the patient (Stehbens, 1988). Because it has a lengthy recovery time as well as extensive periods of

isolation, BMT places children at a relatively high risk for social difficulties (Powers et al. 1995).

The treatment regimen utilized to combat cancer is dependent upon the type, location, and stage of the disease (Jay & Dolgin, 1989; Stehbens, 1988). For example, ALL is usually treated with chemotherapy; CNS radiation is often used in conjunction with the chemotherapy if the child is older than 3 years of age and there is a likelihood of CNS spread of the cancer (Baron et al. 1995; Stehbens, 1988). Survival rates for ALL are said to be approaching 70% (Miller et al. 1994; Stehbens, 1988). On the other hand, ANLL and CML are much rarer and typically more deadly than ALL (Miller et al. 1994; Stehbens, 1988). In fact, despite the use of intensive treatment regimens, ANLL has among the worst survival rates for childhood malignancies at 23% (Miller et al. 1994).

The majority of solid tumors are treated through the use of surgery to excise the tumor, followed by chemotherapy and/or radiation if the disease is in relatively advanced state at time of diagnosis (Cohen & Packer, 1992; Nemes & Donahue, 1994; Shiminski-Maher & Shields, 1995; Stehbens,

1988). A staging system ranging from 1, limited disease, to 4 or 5, extensive disease, is used to classify the severity of many of cancers, such as neuroblastoma, Wilm's tumor, and lymphomas. For example, because diagnosis often fails to occur until after the cancer reaches an advanced state, neuroblastoma frequently has a poor prognosis (Nemes & Donahue, 1994). Survival rates are higher if the neuroblastoma is at an early stage, the patient is less than one year of age at the time of diagnosis, the cancer has not metastasized, and the disease did not arise in the abdominal region (Nemes & Donahue, 1994; Stehbens, 1988). On the other hand, prognosis for Wilm's tumor is generally much better than that of neuroblastoma (Miller et al. 1994; Stehbens, 1988). With the outcome improving substantially during the past 15 to 20 years, children with early stage, nonmetastatic, and favorable histology Wilm's tumors have a 90 to 95% cure rate (Nemes & Donahue, 1994; Stehbens, 1988). When diagnosed in an early stage, the prognosis for those with Hodgkins disease is also highly favorable with 80% of such persons being alive 10 years after diagnosis (Stehbens, 1988).

Although relatively rare when compared to other cancers, liver tumors are among the most deadly pediatric malignancies (Nemes & Donahue, 1994). Cure is limited to cases in which there is a complete resection of the tumor (Nemes & Donahue, 1994). Furthermore, only about 50% of the patients survive more than 5 years even with the addition of chemotherapy and radiation (Nemes & Donahue, 1994). Similarly, bone cancers, such as Osteogenic sarcoma and Ewings sarcoma, are relatively uncommon in children, particularly in those younger than ten years of age (Stehbens, 1988). Treatment for bone cancer typically entails removal of the diseased area, which may necessitate limb amputation, followed by intensive doses of chemotherapy and radiation. Like many other cancers, prognosis is enhanced if the tumor is relatively small and has not metastasized to other bones or regions of the body. Lastly, children with rhabdomyosarcoma are generally considered cured if they are alive two years after diagnosis (Stehbens, 1988). Prognosis for patients with rhabdomyosarcoma is improved if the disease is detected when in an early stage and first occurs before 5 years of age (Stehbens, 1988).

### Coping with Pediatric Cancer

Early studies of coping in pediatric oncology were based on pathological models of coping, which assume that children with cancer are at risk for significant psychopathology (Kupst, 1994). With their emphasis on adjustment difficulties, pathological models left minimal opportunity for examining healthy coping (Kupst, 1994). An example of a pathological coping model used in pediatric oncology is the grief-loss model of coping. This theory is focused on the stages of parental grieving over their child's death, which was believed to be inevitable (Kupst, 1994). Indicating that the majority studies conducted from the grief-loss perspective were scientifically unsound, Kupst (1994) stated that such models were proven incorrect.

The majority of theories currently used in attempts to explore coping within the pediatric oncology population are based on normative models (Kupst, 1994). Normative models view children with illnesses such as cancer as normal individuals in an unusual and stressful situation (Kupst, 1994). One of the most popular normative models of coping is Lazarus and Folkman's (1984) stress-coping theory (Kupst, 1994).

Although initially developed from studying the coping of adult patients with various medical illness, the stress-coping model has been applied to ill children in recent years (Kupst, 1994). Rather than focusing on coping as a trait, the stress-coping model is a process approach which emphasizes the ideas that coping is dynamic, changing, and context dependent (Kupst, 1994; Somerfield & Curbow, 1992). According to the stress-coping model, coping strategies themselves are not good or bad. Instead, the value of coping methods is assessed by determining the extent to which they are effective at reducing and managing stress in a given situation (Kupst, 1994).

Two coping models that have been used with chronically ill children are Varni and Wallander's Disability-Stress Coping Model and Thompson's Transactional Stress and Coping Model (Wallander & Thompson, 1995). In the former coping model, a chronic illness is perceived of as a chronic strain that necessitates frequent readjustment and interferes with normal role activities (Varni, Katz, Colegrove, & Dolgin, 1996). The interactions among risk factors (e.g., stress associated with the disease itself as well as typical life

experiences) and resistance factors (e.g., intrapersonal, social-ecological, and stress-processing characteristics of children and families) help determine how people process and cope with stressful events, including serious illnesses such as cancer (Varni et al. 1996; Wallander & Thompson, 1995). In a similar vein, Thompson's coping model sees cancer as a potential stressor to which a child and his or her family need to adapt, with adjustment being determined by the transactions among biomedical, developmental, and psychological processes (Wallander & Thompson, 1995).

Congruent with the above models, several authors state there is great variability in adjustment to cancer and its accompanying treatment (Somerfield & Curbow, 1992; Spirito, et al. 1991; Stehbens, 1988). In fact, Stehbens (1988) reports that there is no typical patient, usual response to treatment, or best type of coping. Consequently, it is important to have individualized care (Cincotta, 1993). Given that many pediatric oncology patients have a relatively high probability of exhibiting at least transient emotional symptoms during their illness, ongoing assessment of the child

and his or her family is crucial to maximizing adaptive coping (Baum & Baum, 1989; Cincotta, 1993; Noll & Kazak, 1997).

Variables associated with good coping or adjustment include a low level of concurrent stressors, financial security, good familial support, a high degree of family cohesion, and a history of previous effective coping (Brown et al. 1992; Drotar, 1997; Hill et al. 1997; Kupst, 1994; Morris et al. 1997; Varni et al. 1996). Research has consistently demonstrated that low levels of social support (i.e., perceived or actual positive regard expressed by others), lack of communication with respect to diagnosis, a history of poor coping, parental (especially maternal) distress, a central nervous system (CNS) malignancy, and treatment with intracranial radiation are associated with poorer outcomes (Baum & Baum, 1989; Brody, 1991; Drotar, 1997; Duffner & Cohen, 1991; Frank, Blount, & Brown, 1997; Hill et al. 1997; Kazak & Barakat, 1997; Kupst, 1994; Kupst et al. 1995; Last & vanVeldhuizen, 1996; Sawyer et al. 1998; Stehbens, 1988; Varni, Katz, Colegrove, & Dolgin, 1994).

Although the evidence is not as strong as that for the aforementioned variables, other factors such as concurrent



stressors, low socioeconomic status, and functional impairment, also have been found to increase the probability of adjustment problems (Frank et al. 1997; Hockenberry-Eaton & Cotanch, 1989; Kupst, 1994; Kupst et al. 1995; Mulhern, 1989; Varni, Katz, Colegrove, & Dolgin, 1994). Age at diagnosis also appears to have an influence on adjustment, but its effect varies across studies (i.e., some say it is better to be diagnosed when younger while others say it is better to be diagnosed when older) (Kazak and Meadows, 1989; Kupst et al. 1995; Mulhern, 1989). However, most research does indicate that children under the age of 5 are most susceptible to the negative effects (e.g., decreased intelligence, achievement, and memory) of cranial radiation and, to a lesser extent, CNS chemotherapy (Eiser, 1998; Powers et al. 1995).

In summary, the cancers afflicting children are quite varied and include leukemias, brain tumors, neuroblastoma, organ tumors (e.g., kidney and liver), lymphomas, soft tissue malignancies, and bone tumors (Miller et al. 1994; Stehbens, 1988). Factors which influence a pediatric cancer patient's prognosis are disease type, age at onset, and tumor

histology (Nemes & Donahue, 1994; Stehbens, 1988). The most common methods for treating pediatric cancers are chemotherapy, radiation, surgery, and bone marrow transplantation (Stehbens, 1988).

Despite the suggestion of significant psychological difficulties in early psychooncology research, the results of the majority of more recent studies indicates that most children with cancer cope relatively well with their disease (Kupst, 1994). However, numerous cancer variables (e.g., type of malignancy and type of treatment) and subject variables (e.g., concurrent stressors and level of social support) appear to affect the psychological functioning of children with cancer (Baum & Baum, 1989; Duffner & Cohen, 1991; Kupst, 1994; Kupst et al. 1995; Mulhern, 1989; Spirito et al., 1991; Stehbens, 1988; Varni et al. 1994). Therefore, the frequent evaluation of the pediatric cancer patient and his or her family is vital to decreasing the probability of adjustment and coping problems (Baum & Baum, 1989; Cincotta, 1993; Noll & Kazak, 1997).

## Social Development

### Defining Social Development

Social development can be defined as age related changes in a individual's interactions with others (Pettit, 1992). Social development initially occurs within the context of the family, which is the source of the first relationships and social conflicts that a person has with others (Berk, 1989). Beginning at an early age, these reciprocal and bidirectional interactions among children, parents, and siblings are supplemented by relationships with people outside the familial system, such as contact with peers and school experiences (Berk, 1989). As children grow older, peers tend to have an increasing influence upon their behavior; however, the peer group's values tend to be compatible with important adult values (Berk, 1989). Successful socialization during childhood is vital to adult adjustment (Parker & Asher, 1987).

### Theories of Social Development

Historically, virtually all theoretical orientations have theories of social development (Miller, 1989; Pettit, 1992). For example, Erik Erikson, a neo-Freudian, proposed

8 stages of psychosocial development occurring throughout the life-span (Berk, 1989; Miller, 1989). Each of these stages is characterized by a psychological conflict that arises from both maturational forces and societal expectations (Berk, 1989; Miller, 1989; Pettit, 1992). Erickson emphasized that normal development must be understood in relation to each child's life situation and cultural context (Berk, 1989).

At the present time, social learning theory and social information processing theory provide some of the most popular explanations of social development (Miller, 1989; Pettit, 1992). Although the origins of social learning theory were attempts to combine learning theory (i.e., operant and classical conditioning) with psychoanalytic ideas, modern social learning theory is primarily concerned with describing how all behavior, including social behavior, can be explained in terms of reciprocal determinism. Reciprocal determinism can be defined as the belief that the environment (which includes examples of and contingencies for behavior), the person (which includes cognitive factors), and the person's behavior are interdependent and interact to determine

behavior (Grusec, 1992; Miller, 1989). Modern social learning theory is most frequently associated with Albert Bandura (Grusec, 1992, Miller, 1989; Pettit, 1992). While acknowledging that conditioning principles influence behavior, Bandura has chosen to focus on the ways in which observational learning (i.e., learning through watching others) and its cognitive components of attention, retention, production, and motivation, influence behavior (Grusec, 1992; Miller, 1989). Whether or not an observed behavior is reproduced is largely determined by an individual's level of self-efficacy (Bandura, 1977; Grusec, 1992; Miller, 1989). Self-efficacy consists of an individual's belief that he or she can successfully execute a behavior which he or she believes will eventually result in specific, desired outcomes (Bandura, 1977). It should be noted that in recent years social learning theory was been renamed social cognitive theory due to the increasing emphasis on the role that cognition has in affecting behavior (Grusec, 1992; Miller, 1989).

Numerous similarities exist between social cognitive theory and social information processing theories. For instance, both types of theories agree that the interaction

between cognitive factors (e.g. memory, attention, and behavioral enactment skills) and environmental experience is the primary determinate of social development and social behavior (Pettit, 1992; Miller, 1989). Although the gap between these theoretical approaches has narrowed in recent years, social information processing theories have generally been more concerned with individuals' reasoning about their social world, particularly how social information is processed, than has social cognitive theory (Grusec, 1992; Pettit, 1992). In accordance with information processing theory, social information processing theorists are primarily concerned with the flow information through the cognitive system and how the sequence of mental operations changes the social information from input to output (Matlin, 1989; Miller, 1989).

One relatively popular social information processing theory is the Interpersonal Negotiation Strategy Model of Selman and Yeates (1989). According to this model, social development arises from changes in a person's interpersonal negotiation strategies (INS) and role taking abilities as they grow older (Yeates, Schultz, & Selman, 1991; Selman &

Yeates, 1989). These authors define INS as the methods people use in their attempts to resolve conflicting goals in social situations (Yeates et al. 1991; Yeates & Selman, 1989). A series of social information processing steps (SIPS) result in the person deciding on an INS for that particular social situation (Yeates et al. 1991; Yeates & Selman, 1989). The SIPS are (1) defining the problem (2) generating strategies (3) selecting and implementing strategies and (4) evaluating outcomes (Yeates et al. 1991; Yeates & Selman, 1989). Furthermore, what a person does at each of these SIPS depends upon the person's role taking abilities, which are developmentally determined. These role taking abilities range from (0) impulsive (ages 3 to 6)-use of physical means to resolve differences, (1) unilateral (ages 5 to 9)-willful one-way orders or willless submission because of an inability to consider more than one perspective simultaneously, (2) reciprocal (ages 7 to 12)-try to satisfy both persons' goals, to (4) collaborative (ages 10 to 12 and up)-each person modifies his or her goals such that they try to achieve a mutual goal (Selman et al. 1991; Selman & Yeates, 1989). In the INS model, social development is evidenced by

individuals' becoming increasingly able to see themselves in their broader social context and from multiple perspectives (Selman & Yeates, 1989).

Table 1  
Theories of Social Development

		<u>Theories</u>	
	<u>Erickson</u>	<u>Social Learning Theories</u>	<u>Interpersonal Negotiation Strategies</u>
<u>Characteristic</u>			
reciprocal determinism	marginal	yes	yes
self efficacy	no	yes	no
biological emphasis	yes	marginal	marginal
cognitive emphasis	no	yes	yes
SIPS	no	no	yes
role taking abilities	no	no	yes



### Social Competence

#### Defining and Studying Social Competence

Social competence and social development are related phenomena. Since what is considered socially competent behavior depends upon a person's age, assessment of an individual's level of social competence is linked to his or her level of social development (Crick & Dodge, 1994; Yeates & Selman, 1989). Social competence is said to arise from a person's experiences in close relationships (Hartup, 1989). Although there is no agreed upon definition of social competence, many authors indicate that there are two main commonalities across definitions and theories: (1) social competence involves social skills (i.e., the socially acceptable, learned verbal and nonverbal abilities engaged in in social contexts which elicit positive responses and inhibit negative ones) but is not limited to them and (2) social competence refers to the efficacy and adequacy of a person's social interactions (Dodge, 1989; Elliot & Gresham, 1993; Gresham, 1998; Spirito, et al. 1991).

The most popular models of social competence, which will be discussed shortly, note that cognitive processes,

especially SIPS, are vitally important for socially competent behavior (Cavell, 1993; Crick & Dodge, 1994; Selman & Yeates, 1989). Cavell (1993) asserts that SIPS can be separated into the three broad categories of encoding skills (i.e., attending to and interpreting stimuli), decoding skills (i.e., generating strategies), and enactment skills (i.e., executing the chosen behavior and evaluating its effectiveness). A definition of social competence which contains most of the characteristics described above is that of Yeates & Selman (1989) who define social competence as:

knowledge, including the capacity for emotional control, that mediate behavioral performances in specific contexts, which in turn are judged by self and others to be successful and thereby increase the likelihood of positive psychosocial adjustment (p.66).

In other words, social competence can be best conceptualized as the possession of the age-appropriate social-cognitive and behavioral skills necessary to meet ones' goals in social situations while simultaneously maintaining positive relationships with other individuals.

Greenspan (1982) stated that there are three primary approaches to studying social competence, namely the outcome, content, and skills approaches. The outcome approach

is concerned with the ability of individuals to attain social objectives, such as having friends, doing adequately in school, and having at least average peer status (Greenspan, 1982). Greenspan (1982) argues that outcome variables are often good indicators of social status, but they do not tell you the cause of the social problems. The content approach consists of attempts to identify behavioral traits that are associated with positive and negative social outcomes; examples of such traits include sociability, emotionality, and social anxiety (Greenspan, 1982). It should be noted that girls have been found to report more social anxiety than boys (LaGreca & Stone, 1993). Lastly, the skill approach involves studying a person's level of social awareness or social intelligence, which Greenspan (1982) defined as one's understanding of the interpersonal processes used to gain social acceptance. The skill approach is comprised of the three categories: (1) social sensitivity-the ability to accurately label the meaning of a social event, (2) social insight-the ability to understand the processes underlying social events and make evaluative judgments about them (i.e., why is something happening in a specific social situation),

and (3) social communication-the ability to understand how to intervene effectively in social situations (Greenspan, 1982). Examples of social sensitivity, social insight, and social communication are role taking, social comprehension, and social problem solving, respectively (Greenspan, 1982).

#### Theories of Social Competence

The three most prominent theories or models of social competence are the Interpersonal Negotiation Strategy Model of Selman and Yeates (1989), the Social-Information Processing Model of Crick and Dodge (1994), and the Tri-Component Model of Cavell (1990).

The majority of the basic components of Selman and Yeates' (1989) INS model were described in the social development section. To briefly summarize, these authors emphasize that the methods by which individuals resolve differences in social situations (i.e., their interpersonal negotiation strategies or INS) are linked to developmental changes in role-taking abilities; these changes can reportedly be observed by studying differences in the four SIPs across age groups (Selman & Yeates, 1989). Yeates and Selman (1989) assert that although role taking abilities are

generally at one of the four levels, these can vary depending upon the person's experience with the particular situation in question, which is reflected in their database of information. Consequently, they view social competence as domain specific and, therefore, claim that one must be careful to avoid making unfounded generalizations about social behavior based on information from one or even a few social settings (Yeates & Selman, 1989). Advancement in role taking abilities is said to be most likely to occur when the individual attempts to determine why his or her lower level strategies failed to produce desired results in a given social situation (Yeates and Selman, 1989). Indicating that social competence is ultimately defined in terms of long-term adjustment rather than short-term social functioning, Selman & Yeates (1989) say that other theories, including Crick & Dodge's (1994), are inadequate because they do not give a satisfactory account of the means of developmental changes in social reasoning. In two studies, Yeates et al. (1991) used an interview format to obtain peer status and INS levels from of a sample of elementary and middle school students. The INS level of each child was calculated by

analyzing the subject's answers (Yeates et al. 1991). These authors reported that their findings supported their assertions that there are age differences in INS, that INS are often situation specific, and that INS are related to social competence (Yeates et al. 1991).

Although the models of social functioning espoused by Yeates and Selman and Crick and Dodge (1994) include discussion of information processing in social situations, the latter model places considerably more emphasis on information processing. According to Crick and Dodge (1994), each individual has biologically based capabilities as well as a database of past experience, which they continually consult while interpreting a social situation. The six SIPS in social situations are (1) encoding cues, (2) interpreting the cues, (3) clarifying and selecting goals for the situation, (4) constructing responses, (5) evaluating responses and selecting the one with the most positive evaluation, and (6) behavioral enactment (Crick & Dodge, 1994). They indicate that although described as sequential, these SIPS are really cyclical and actually occur simultaneously (Crick & Dodge, 1994). Crick and Dodge (1994) acknowledge the likelihood of

increased speed and automaticity of processing as individuals get older; however, unlike Yeates & Selman (1989), they do not clearly specify the existence of developmentally-based differences in social reasoning abilities. Dodge and Price (1994) cite numerous studies that appear to be supportive of their six SIPS. In particular, they provide evidence of problems in various SIPS among children with social difficulties (Dodge & Price, 1994). For example, they indicate that socially incompetent children are less attentive to social cues, access fewer competent responses, and are worse at enacting responses when compared to children with average or above average peer status (Dodge & Price, 1994).

The third and last theory of social competence that will be discussed is Cavell's (1990) Tri-Component Model of social competence. As noted in the section defining social competence, Cavell (1990) separates social information processing into the three areas of encoding skills, decision skills, and enactment skills. Similar to Selman and Yeates' (1989) claim that social competence is situation specific, Cavell (1990) emphasizes the importance of focusing on typical behavior on relevant tasks rather than on behavior in

artificial situations. According to Cavell (1990), social competence is hierarchically arranged. Ranging from lowest to highest, the three components of social competence are (1) social skills-the specific abilities/social information processing skills that allow a person to perform competently on a social task, (2) social performance-the degree to which a person's responses meet socially valid criteria in given situations, and (3) social adjustment-the extent to which a person is achieving socially determined, developmentally appropriate goals. Social adjustment is evaluated by looking at the products of social functioning, such as global judgments of competence and level of peer acceptance (Cavell, 1990). Cavell (1990) states that the identification of children at risk for social functioning difficulties is most efficient if the researcher or clinician first assesses the child's social adjustment in a broad range of social contexts. If social adjustment problems were detected, such as low peer status, one would then proceed to conduct a situational analysis of the problematic situations in order to determine the child's deficits in the information processing steps (Cavell, 1990). The Tri-Component model suggests that



investigators should be careful to avoid basing judgments of social competence on only a portion of relevant data, such as using measures that assess social adjustment but not social performance or social skills (Drotar, Stein, & Perrin, 1995).

Table 2 presents a summary comparison of the major components of these three models.

Table 2  
Theories of Social Competence

<u>Characteristic</u>		<u>Models</u>	
	<u>Cavell</u> (1990)	<u>Crick &amp; Dodge</u> (1990)	<u>Yeates &amp; Selman</u> (1989)
IPS	Yes	Yes	Yes
Directionality- linear or circular	Both	Circular	Both
Developmental Emphasis	No	No	Yes
Database	No	Yes	Yes

### Social Functioning

#### Friendship and Peer Relations in Childhood

Relationships with others are a primary component of and have a strong influence upon social functioning. Having several important functions in our lives, relationships with other individuals, including both friends and the overall peer group, have an impact on both short and long term adjustment (Coie & Cillessen, 1993; Parker & Asher, 1987; Spirito et al. 1991). Relationships with others are one of the primary means through which children acquire social knowledge and enhance social skills (Furman & Robbins, 1985; Hartup, 1989).

While friendships and peer relations provide similar types of benefits to individuals, these two types of interactions are not equivalent (Parker & Asher, 1987). For example, children can be accepted by their peer group but have few close friends or have several close friends but be rejected by their peer group (Parker & Asher, 1987; Furman & Robbins, 1985). Both peer relations and friendships become increasingly abstract, stable, and complex as children grow older (Erwin, 1993a; Hartup, 1989). However, when compared

to general peer relations, friendships are better sources of intimacy, loyalty, companionship, reciprocity, and affection (Furman & Robbins, 1985; Hartup, 1989; Bierman & Montminy, 1993). On the other hand, since feeling included is dependent upon the existence of a group and a friendship typically involves a limited number of people, peer relationships are superior to friendships in providing a sense of inclusion (Furman & Robbins, 1985).

Although there are numerous ways to study children's relationships with their peers, the most common means is to measure peer acceptance (LaGreca, 1993). Children with low peer status/low levels of peer acceptance are typically described as either rejected (i.e., actively disliked), neglected (i.e., neither liked nor disliked), or controversial (i.e., both strongly disliked and liked) (Volling, MacKinnon-Lewis, Rabiner, & Baradaran, 1993). By far the most frequently studied group of low status children, rejected children, can be further divided into the categories of aggressive, withdrawn, and undifferentiated (Coie & Cillessen, 1993). The results of several longitudinal studies suggest that among low status children, aggressive-rejected

children, who have been found to be more likely than their nonaggressive peers to make hostile interpretations of ambiguous situations, have the poorest long-term outcomes and exhibit the highest degree of behavior problems, especially externalizing ones (DeRosier, Kupersmidt, & Patterson, 1994; Hymel, Rubin, Rowden, & Lemare, 1990; Kupersmidt & Patterson, 1991; O'Neil, Welsh, Parke, Wang, & Strand, 1997; Taylor, 1989; Webster-Stratton & Lindsay, 1999). O'Neil et al. (1997) found that children who were stably rejected (i.e., rejected for two or more consecutive years) did worse socially, behaviorally, and academically than those who were transiently rejected (i.e., rejected one year but not the next).

Volling et al. (1993) and Newcomb, Bukowski, and Pattee (1993) note that aggression alone is insufficient for peer rejection. Instead, a child must be aggressive and have deficits in prosocial skills. Prosocial skills include being cooperative and friendly and having good social problem solving skills and group entry abilities (Berk, 1989). Consequently, controversial children appear to do reasonably well socially because their aggressive behavior is at least

partly attenuated by their typically average level of prosocial and cognitive skills (Newcomb et al. 1993).

Additional research has documented that all types of low peer status children have deficits in their social information processing skills (Brochin & Wasik, 1992; Dodge & Price, 1994; Erwin, 1994; Kurdek & Krile, 1982; Mott & Krane, 1994). In particular, these authors note that the solutions developed by low status youth for social situation are often less competent (i.e., achieving goals in socially undesirable ways) and less effective (i.e., not achieving goals in the situation) when compared to solutions developed by their average status and high status peers.

#### Assessment of Social Functioning

According to Foster, Inderbitzen, and Nagle (1993) and Oglivy (1993), several different methods can be used to assess social functioning. These authors state that these assessment techniques can be classified into four broad categories: direct observation, social problem solving, assessment by others, and self-report. Direct observation has the advantage of enabling the clinician to examine the contingencies that are likely maintaining behavior; however, there

are several limitations to direct observation including relatively low levels of experimental control, obtrusiveness, dependence upon the natural occurrence of the behavior, sampling problems, and the fact that this method does not allow the investigator to determine the exact nature of the behavior problems (Foster et al. 1993; Oglivy, 1993). Analogue tasks, which are contrived situations designed to elicit the responses of interest, can overcome some of the drawbacks of direct observation (Foster et al. 1993; Oglivy, 1993).

Although their reliability and validity are often questioned, social problem-solving techniques involve attempts to formally assess children's social problem solving skills through analyzing the child's responses to hypothetical social dilemmas (Oglivy, 1993). Self-report techniques consist of the child evaluating his or her own behavior through the completion of questionnaires or by answering interview questions (Foster et al. 1993; Oglivy, 1993). Foster et al. (1993) state that judgments of social functioning should not be based solely on self-report since self-report measures

often have very global questions and self observation can be poorly correlated with behavior.

Evaluations by others are a common technique for assessing social functioning (Foster et al. 1993). Sociometric methods involve teachers, parents, or peers rating children on their ability to fulfill certain roles. Sociometric techniques look at peer status along the two dimensions of (1) social preference/social likeability or the degree to which children are liked or disliked by peers and (2) social impact/social salience or the degree to which youth are noticed by their peers (Newcomb et al. 1993). Although these methods are face valid and relatively easy to complete, sociometric techniques can lead to negative labeling, are often inaccurate with younger children, and they do not tell you the source of the child's peer difficulties (Bierman & Montminy, 1993). Unfortunately, sociometric measures are often difficult to obtain in the typical clinical setting. Lastly, social skills, a component of social functioning, are typically assessed via self-report or evaluation by others (Foster et al. 1993; Oglivy, 1993).

### Interventions for Children with Social Difficulties

In a metanalytic review of social competence training studies, Beelman, Pfingsten, & Losel (1994) indicated that the four most commonly used techniques for improving social competence are (1) social problem solving-learning to generate solutions and use means-end thinking, (2) role taking-focusing on the development of social perspective taking, (3) self-control training-enhancing the child's ability to evaluate solutions prior to enactment, and (4) social skills training. The first three types of interventions have been found to have significant, relatively small short-term effects and marginal long-term effects (Beelman et al. 1994; Schneider, 1992). Several authors note that social competence training techniques that have a relatively strong cognitive emphasis, such as social problem solving and self-control training, are less effective with children under 7 years of age (Beelman et al. 1994; Elliot & Gresham, 1993; LaGreca, 1993; Oglivy, 1994; Schneider, 1992).

Social skills training (SST) is by far the most common method for modifying problematic social functioning (Beelman et al. 1994; Elliot & Gresham, 1993; LaGreca, 1993; Oglivy,



1994; Schneider, 1992). The assumptions in most SST programs are (1) that children who have problems in social relations lack appropriate social skills; (2) that it is possible to teach social skills; and, (3) that children who learn social skills will demonstrate improvements in their social functioning (Gresham, 1998; Katz & Varni, 1993; Oglivy, 1994). The four main types of SST interventions are problem solving, contingency management (i.e., using operant and classical conditioning methods), modeling (i.e., a social learning theory method in which the desired behavior is demonstrated to the child), and coaching (i.e., a cognitive-behavioral method consisting of verbal instruction followed by practice and feedback) (Elliot & Gresham, 1993; Erwin, 1993b, Gresham, 1998; Oglivy, 1994).

Gresham & Elliot (1993) state that selection of the SST method should be depend to some extent on whether the child has a knowledge deficit (i.e., lacks the skills needed for appropriate interactions) or a performance deficit (i.e., the inadequate application of knowledge and skills in social situations). Most social skills difficulties are due to a performance deficit (Gresham, 1998). SST programs seem to

work best if they are multifaceted (i.e., include several sources of information and multiple intervention techniques) as well as socially valid (i.e., extent to which targeted behaviors are important to social functioning) (Gresham, 1998; Blonk, Prins, Sergeant, Ringrose, & Brinkman, 1996). Coaching has been found to be the most effective method for improving social functioning; however, it is considerably less successful with children under the age of 7 (Elliot & Gresham, 1993; Oglivy, 1994; Schneider, 1992). The difficulties many children under the age of 7 have with coaching is attributable to their level of cognitive functioning, which does not yet contain the logical, abstract reasoning capabilities and role taking abilities thought to be requisites for cognitive techniques (Kinney, 1991).

Although SST programs are based on the idea that teaching social skills will lead to improvements in social behavior, this is not always the case (Elliot & Gresham, 1993; LaGreca, 1993; Oglivy, 1993). One possible explanation for the lack of change in peer status despite improved social skills is group dynamics. Examples of such group dynamics are the persistence of attributional biases, such as the

proclivity to view the behavior of low status peers negatively even when presented with contradictory evidence, and the tendency of peers to fail to reinforce low status peers for prosocial behaviors (Coie & Cillessen, 1993; LaGreca, 1993; Volling et al. 1993). Procedures that can help counteract group dynamics as well as increase the effectiveness of SST include having peers participate in the intervention, establishing behaviors that are likely to be maintained by naturally occurring contingencies in the environment, and providing training in skills which have social validity (Gresham & Elliot, 1993; Oglivy, 1993). In addition, it should also be noted that while rejected children have been the most extensively studied subtype of low status youth, withdrawn children appear to have the best response to all types of social competence training (Elliot & Gresham, 1993; Oglivy, 1994; Schneider, 1992). This finding is particularly promising for those working with pediatric cancer patients since the most frequently observed social problems within this population have been social isolation (Kupst 1994; Noll et al. 1990; Noll et al. 1993; Spirito et al. 1990).

In summary, relationships with others, including family members, friends, and the peer group, strongly influence both social functioning and psychological adjustment (Coie & Cillessen, 1993; Parker & Asher, 1987; Spirito et al. 1991). Children with poor peer relations have low levels of acceptance by their peers (LaGreca, 1993). Children who both lack prosocial skills and are aggressive have the worst prognosis among all low status youth (Coie & Cillessen, 1993; LaGreca, 1993; Newcomb et al. 1993; O'Neil et al. 1997). A wide variety of techniques exist for evaluating the social functioning of children thought to be at risk for social problems (Foster et al. 1993; Oglivy, 1994). These assessment methods range from observations by others to self-report measures (Foster et al. 1993; Oglivy, 1994). Methods for modifying problematic social behavior include social problem solving, role taking, self-control training, and social skills training (Beelman, et al. 1994; Erwin, 1993b; Schneider, 1992). With success depending upon the ability to counteract group dynamics, social skills training has the largest effect sizes of these intervention methods, especially when non-cognitively oriented methods are used

with children under the age of 7 (Elliot & Gresham, 1993; LaGreca, 1993; Oglivy, 1993; Schneider, 1993).

#### Research on Psychosocial Adjustment to Cancer

In recent years, numerous studies have been conducted which attempt to examine psychosocial adjustment in pediatric cancer patients. As both the short and long-term survival rates for many pediatric malignancies have improved, studying the psychosocial adjustment of children with cancer has taken on increased importance (Kupst, 1994; Rowland, 1989; Wallander & Thompson, 1995). The ultimate goal of most psychosocial research is to try to identify variables which influence an individual's quality of life, which can be defined as the amount of satisfaction a person has with his or her present life circumstances (Belec, 1992). The past, expectations of the future, and the person's psychological, social, economic, and health status all have an impact on quality of life (Belec, 1992).

The initial seminal work by Koocher and O'Malley (1981) suggested that approximately 50% of childhood cancer survivors experience at least mild psychological symptoms and, by inference, adjustment problems (Kupst, 1994). However, the

majority of more recent studies imply that long-term adjustment among pediatric cancer patients is generally adequate (Kupst, 1994; Spirito et al. 1990). In fact, it should be noted that the overall adjustment of cancer survivors has been found to be similar or superior to the adjustment of children with other chronic pediatric conditions (Lavigne & Faier-Routman, 1992).

Several investigators have examined the social adjustment of pediatric oncology patients. Spirito et al. (1990) studied the social adjustment of cancer survivors initially treated between 2 and 5 years of age. When assessed at 5 to 12 years of age, there were no significant differences when compared to controls in terms of the cancer children's view of their competencies. However, the authors did indicate that the children with cancer reported greater isolation than their healthy peers (Spirito et al. 1990). Kazak and Meadows (1989) also examined the adjustment of pediatric cancer survivors who were relatively young at diagnosis (i.e., mainly during the preschool years). Ranging from 10 to 15 years of age, the children in this latter study did not differ from test norms with respect to their report of

child behavior, perceived competence, family functioning, and social support (Kazak & Meadows, 1989). Yet, it is noteworthy that there was some indication that the availability of social support had decreased somewhat over time (Kazak & Meadows, 1989).

Noll and colleagues have conducted several investigations into the social functioning of children with cancer (Noll et al. 1990; Noll et al. 1992; Noll et al. 1993). The primary measure in all three of these studies was the Revised Class Play or RCP, which is a measure that looks at the ability of children to fulfill certain roles. Derived from the responses, the three scales on the RCP are Sociability-Leadership, Aggressive-Disruptive, and Sensitive-Isolated (Noll et al. 1990; Noll et al. 1992; Noll et al. 1993). Involving children between 8 and 18 years of age, the subjects' cancer status ranged from on active treatment (Noll et al. 1992) to maintenance treatment/recent treatment termination (Noll et al. 1990) to off treatment (Noll et al. 1993). The results of all three studies documented no elevations on aggression and some indications of social isolation. The authors pointed out that despite the increased

levels of social isolation, there was no evidence of difficulties with social acceptance, depression, or self-concept (Noll et al. 1993).

In a more recent study, Noll et al. (1997) found no differences in behavioral or academic adjustment between ALL cancer survivors who received chemotherapy and radiation versus those who received chemotherapy only. While contrary to other research, the authors suggested that the lack of a radiation effect may be due to the relatively low doses of radiation received by the children (Noll et al. 1997).

Recent research by Vannatta and colleagues documented some social differences between 8 to 16 year old BMT survivors and classroom matched controls (Vannatta, Zeller, Noll, & Koontz, 1998b). Specifically, the BMT children had fewer friends and were described by their peers as more socially isolated, less attractive, and less athletically competent than their healthy classmates (Vannatta et al. 1998b). Cranial irradiation (CRT) was associated with higher levels of social withdrawal and anxiety (Vannatta et al. 1998b). Several other researchers have also found a positive relationship among CRT, school/academic problems, and psychological



distress, but they indicate that these difficulties are typically subclinical in nature (Adamoli et al. 1997; Hill et al. 1998). Interestingly, intrathecal chemotherapy is not associated with a significant decrease in academics despite having contact with the CNS (Brown et al. 1998; Copeland, Moore, Francis, Jaffe, & Culbert, 1996).

Pendley, Dahlquist, and Dryer (1997) looked at the relationship between body image and social adjustment among adolescent cancer survivors and healthy controls. The cancer survivors engaged in half the number of social activities as their healthy counterparts (Pendley et al. 1997). However, of greater concern was that children with cancer who thought their illness had had a negative effect on their physical appearance reported relatively high levels of loneliness and social anxiety (Pendley, et al. 1997).

Congruent with earlier studies, two group of researchers have found evidence of increased adjustment difficulties among children who have survived brain cancer (Radcliffe, Bennett, Kazak, Foley, & Phillips, 1996; Vannatta, Gartstein, Short, & Noll, 1998a). Although 6 to 18 year old brain tumor survivors scored within the normal range on

self-report measures of depression, anxiety, and self concept, their mothers reported increased social problems, decreased social competence, decreased school competence, and decreased communication skills relative to test norms (Radcliffe et al. 1996). The children did describe themselves as less athletically competent than healthy youth (Radcliffe et al. 1996). Vannatta et al. (1998a) used the Revised Class Play (RCP), likeability ratings, and number of friends in their effort to study the social functioning of 8 to 18 year old brain tumor survivors. Despite the fact that the study participants represented the best medical outcomes within the brain tumor survivor sample (i.e., primary school placement was in a regular rather than special education classroom), the brain tumor survivors still had fewer friends and were more socially isolated than the healthy controls (Vannatta et al. 1998a).

While children with newly diagnosed cancer have been found to have a higher level of internalizing problems relative to healthy controls, these difficulties seem to dissipate by one year post-diagnosis (Sawyer, Antoniou, Toogood, & Rice, 1997; Sawyer et al. 1995). Consistent with previous

research, Varni et al. (1994) found that recently diagnosed cancer patients had better self-esteem, less social anxiety, and a lower level of psychological distress if they had a higher level of social support. Katz and Varni (1993) developed a social skills program designed to address areas thought to be important in adjustment of children with newly diagnosed cancer; these three areas were teasing/name calling, assertiveness, and social cognitive problem-solving. Subsequently, Varni, Katz, Colegrove, and Dolgin (1993) demonstrated that newly diagnosed cancer patients who participated in their social skills intervention reported higher levels of social support and, according to parental report, decreased behavior problems and improved school competence at nine month follow-up. In contrast, the controls, who were enrolled in a standard school reintegration program, failed to show similar improvements. The findings of Varni et al. (1993) suggest that interventions aimed at improving the adjustment of children with cancer can be successful.

However, there are some shortcomings or inadequacies in the current studies of psychosocial adjustment among pediatric oncology patients. One criticism of presently available

studies is the frequent failure to take into account individual characteristics, such as age or stage of illness, which may influence outcome (Armstrong, 1995; Drotar, 1994, Kupst, 1994; Spirito et al. 1991). For example, due to sample size limitations, developmental issues have been largely ignored in research (Armstrong, 1995; LaGreca, 1990; Siegel, 1990; Spirito et al. 1991). Because younger children have been found to exhibit more distress than older children, failure to include developmental issues in studies may have resulted in an overly optimistic picture of the adjustment of younger patients, especially during the treatment phases of their illness (Varni & Katz, 1987). In fact, the exclusion of many subject and disease variables from investigations has increased the probability that some researchers have made incorrect interpretations of their findings (Armstrong, 1995; Drotar, 1994; Kupst, 1994).

Another problem in the psychosocial adjustment research is the questionable appropriateness of measures frequently used to assess the psychological functioning of pediatric oncology patients (Siegel, 1990; Drotar et al. 1995; Spirito et al. 1991). For instance, Drotar et al. (1995) suggest

that the Child Behavior Checklist (CBCL), a parent-report measure designed to screen for psychopathology, may yield inaccurate information when used with chronically ill children. In particular, some of the indices of social functioning on the CBCL, such as involvement in various activities, may underestimate the social competence of children with cancer due to disease-related restrictions in these areas (Drotar et al. 1995). Drotar et al. (1995) note that children with cancer may demonstrate their social competence in ways not measured by the CBCL, such as knowledge about activities rather than participation. In addition, the CBCL's relative insensitivity to less serious difficulties (i.e., mild affective symptomatology and marginal adjustment issues), which are the most frequent type of problem experienced by children with cancer, may result in a failure to detect problems worthy of intervention (Drotar et al. 1995).

In summary, the majority of recent studies suggest that most children who survive cancer do not experience significant adjustment difficulties (Kupst, 1994). The most commonly documented social difficulty among pediatric oncology patients is an increased level of social isolation relative

to their peers (Noll et al. 1990; Noll et al. 1993; Spirito et al. 1990; Vannatta et al. 1998a; Vannatta et al. 1998b). Social skills training has been found to be effective in decreasing problematic behavior and increasing social support in newly diagnosed pediatric cancer patients (Varni et al. 1993). Unfortunately, developmental issues, stage of illness, and measure appropriateness have been largely ignored in many investigations (Armstrong, 1995; Drotar et al. 1995; Kupst, 1994; Varni & Katz, 1987).

#### Rationale and Hypotheses

While the currently available research has greatly expanded our understanding of psychosocial adjustment to cancer during childhood, there is still much more that needs to be learned. Given children with cancer have a relatively high probability of experiencing social difficulties due to the numerous short-term and long-term alterations in functioning associated with their diseases, programs addressing social functioning within this population appear to be warranted (LaGreca, 1990). Unfortunately, funding is limited. Therefore, it is important to determine if currently available measures result in an accurate assessment of variables

that might increase the probability of social problems for pediatric oncology patients (Kupst et al. 1995; LaGreca, 1990). Additionally, assessing whether the influence of disease and individual characteristics varies depending upon the stage of the illness would be extremely useful in the development of social interventions. Thereafter, the social programs could then be targeted at the children who have the strongest need for such services.

One purpose of this study was to examine the relationship between stage of illness and social adjustment in pediatric oncology patients. A second purpose of this investigation was to try to determine what combination of characteristics are associated with social functioning in pediatric oncology patients. This was accomplished by examining the relationships between social adjustment and the various participant, disease, and psychological variables included in the study. Lastly, the concurrent validity of the Social Adjustment Inventory for Children and Adolescents (SAICA) was assessed by studying its relationship to the Social Competence Scale of the CBCL. The information gathered from this investigation can hopefully be used to direct resources

towards the pediatric oncology patients in greatest need of social intervention.

It should be noted that in accordance with his Tri-Component Theory of social competence, Cavell (1990) suggested that the identification of children at risk for social functioning difficulties is most efficacious if the clinician first assesses the child's social adjustment in a broad range of social contexts. If social adjustment problems are detected, then the clinician would try to determine the child's deficits in the social-information processing steps mentioned in the various theories of social competence (Cavell, 1990; Dodge & Crick, 1994; Yeates & Selman, 1989). Congruent with the ideas of Cavell (1990), this study focused on the social adjustment of pediatric cancer patients across various domains. However, in order to increase the feasibility of the current study, the examination of social information processing skills was not included in the current investigation. This exclusion notwithstanding, the present study has the potential to clarify variables that should be incorporated into social interventions.



Several hypotheses in this study are based on the findings of previous research concerning psychosocial adjustment to cancer. The six hypotheses specifically related to cancer variables that were addressed are:

(1) As a group, children with cancer will not differ significantly on social functioning measures as compared to non-chronically ill controls.

(2) The social adjustment of children with cancer will be related to the following illness variables: (a) stage of illness, (b) disease type, (c) disease status, and (d) illness-related restrictions in social contact.

(2a) Stage of illness will be related to the social functioning of children with cancer, with those who have finished their treatment protocol having better social adjustment than the children still completing treatment or the children with residual effects from their disease.

(2b) Children with cancers that do not primarily involve the CNS will have better social functioning than children with brain tumors.

(2c) Children who are in their initial experience with cancer will have better social functioning than those who have had disease recurrence.

(2d) Children with cancer who have a relatively low level of illness-related restrictions in social contact will have better social functioning than those with a relatively high level of illness-based restrictions in social contact.

(3) Children with cancer who do not have a psychiatric diagnosis will have better social functioning than those with a psychiatric diagnosis.

(4) Because cancer and its treatment can decrease a child's opportunity for social contact with other children, children with cancer are expected to report lower levels of social support from peers as well as higher levels of social anxiety when compared to healthy controls.

The remaining hypotheses in this study are primarily based upon research concerning the relationships among demographic variables, social functioning, and psychosocial adjustment. Applicable to both the Cancer and Control Groups, these hypotheses are:

(5) Older children will have better social functioning than younger children.

(6) Children with higher levels of social support from peers will have better social functioning than those with lower levels of social support.

(7) Children who are female and/or younger will report greater social anxiety than children who are male and/or older.

(8) Children with less social anxiety will have better social functioning than those with more social anxiety.

## METHOD

### Participants

Participants were children between 5 and 12 years of age. Two groups of children were recruited for this investigation. Group 1 (Cancer) consisted of 80 children diagnosed with cancer. Children who were in palliative care or could not be classified into one of the five stage of illness categories were excluded from the study. It should be noted that data from one child with cancer could not be used due to the recency of his diagnosis (i.e., the study data were obtained less than two weeks after the child was diagnosed). In addition, the assessment batteries of three children with cancer were incomplete because of missing parent questionnaire data (two cases) and questionable child report (one case). This resulted in the full assessment battery being available for 77 of the children with cancer. Only 10 of the 91 families of children with cancer who were approached regarding the study declined to take part, resulting in an 89% participation rate.

Group 2 (Control) consisted of 95 healthy school-aged children recruited from the city where the Health Science Center is located. All children in the Control Group had no known severe chronic illnesses or psychological diagnoses. Approximately 220 local families were approached regarding the study, with half of them agreeing to participate. Unfortunately, data from 25 of the healthy children were not useable due to questionable responding from parents and/or children. A total of 95 children successfully completed the child measures. However, two of the healthy-child assessment batteries were incomplete due to missing parent data. Therefore, the full assessment battery was obtained for 93 Control Group participants.

#### Measures

The main objective of the present investigation was to examine the relationships among participant variables, disease variables, psychological variables, and the overall social adjustment of pediatric cancer patients. The variables believed to be associated with social functioning included several individual characteristics, disease characteristics,

social anxiety, and social support. Table 3 presents a brief description of the measures that were used in this investigation and the age group to which they apply. All of the measures were only used with children ages 5 to 12 even if they were applicable to other ages as well.

Table 3  
Measure Information

<u>Measure</u>	<u>Age Range</u>	<u>Domain Assessed</u>
Demographic Questionnaire	5 to 18	subject demographics
Cancer Questionnaire	5 to 18	cancer variables
SSS	8 to 14*	social support
SASC-R	6 to 12*	social anxiety
CBCL	4 to 18	social competence & behavior problems
SAICA	6 to 18*	social adjustment

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\* Although developed for children over 5 years of age, these measures were chosen because an examination of the items revealed that these questionnaires adequately capture the social functioning of late preschool and kindergarten age children. As described in the procedure section, the questionnaires were read aloud to the children and the examiner was provided with a list of standard synonyms which could be used to define words that were not understood by the child.

### Predictive/Independent Variable Measures

Many participant characteristics served as predictive variables in the present investigation. A Demographic Questionnaire to record these variables was developed for this study (Appendix A). Demographic variables and other participant characteristics, such as age, gender, ethnic background, socioeconomic status, family structure (i.e., the number of adults in the home and their roles with respect to the child), family duration (i.e., how long the current family structure has been in existence), family size (i.e., the number of children living at home), and preexisting psychopathology in the child, were gathered from questions on the demographic questionnaire. Socioeconomic status (SES) was assessed by asking if families were receiving federal assistance.

For the Cancer Group participants, disease variables, including the child's specific diagnosis, age at diagnosis, illness duration, treatment types, disease type, disease status, stage of illness, and illness-related restrictions in social contact were obtained from interview inquiries,

reviewing the participants' medical records, and questions on both the demographic and cancer forms. Three categorical disease variables of interest for the children with cancer, namely stage of illness, disease status, and disease type, served as predictive variables in this study. The stage of illness variable consisted of the five groups of early, middle, late, stable, and post-treatment, respectively. The data manager at the University of Florida Cancer Center provided the examiner with the typical protocol length and illness stages for the diseases; these data were used to help classify the children into one of the five stage of illness groups. The medical respondent was asked to take the above illness characteristics into account when determining the stage of illness for each child. Since illness duration and stage of disease are not equivalent across cancers, illness duration was also measured. The disease status variable involved the two categories of initial diagnosis and recurrent disease. Lastly, the disease type variable consisted of the two categories of central nervous system disease (CNS)/brain tumors versus cancers that do not primarily involve the CNS.



An illness-related restrictions in social contact score was assigned to each child with cancer. This score was calculated by asking the medical respondent to assess the extent to which both disease-related physical limitations and decreased immunological functioning were influencing the child's potential for social contact. The medical respondent was asked to take the child's diagnosis and treatment protocol into account when responding to the brief, 2-item questionnaire regarding restrictions in social contact. The measure was most often completed verbally, with the examiner asking the questions and the respondent providing verbal instead of written responses. Having a YES/NO format, the answers to these four questions were combined into a summary score that serves as the illness-related restrictions in social contact variable. This social restrictions score can range from 4 to 8, with higher scores representing fewer disease-related limitations in social contact. The top portion of the Cancer Questionnaire included space for the examiner to record many of the disease-related variables described previously (Appendix B).

### Outcome Variable Measures

Two measures were used to assess general social functioning, the main outcome or dependent variable in this study. The dependent measure of primary interest was the Social Adjustment Inventory for Children and Adolescents (SAICA). Developed by John, Gammon, Prusoff, and Warner (1987), the SAICA is a measure designed to assess the social adjustment in youngsters ages 6 to 18. However, with the exception of some items on the school scale, this measure would also seem to apply to slightly younger children as well. The SAICA can be completed by a child as a self-report measure or by a parent about his/her child. While designed as a semi-structured interview, the SAICA can be self-administered to children 10 years and older. Taking approximately 30 minutes to complete, the test consists of 71 questions (41 problem items and 30 competence items), which are each rated on a scale from 1 to 4. The items are either read aloud by the examiner or read silently by the subject, depending upon his/her reading ability. Each of the questions is presented in the structured alternative

format developed by Harter (1982). Designed to counteract the tendency to respond in a socially desirable manner, the structured alternative format requires the respondent to first decide whether the positive or negative phrasing of of the same statement fits him/her best and then indicate if his/her choice is sort of true or really true. On the SAICA, the child or parent rates the child's functioning in the four role areas of school, peer relationships, sparetime activities, and home adjustment. The home adjustment area is further subdivided into relations with parents and siblings. A heterosexual subsection is included for children 13 years and older. Consequently, the six possible subscales are School Functioning, Peer Interactions, Sparetime Functioning, Heterosexual Interactions, Interactions with Siblings, and Interactions with Parents. In addition, one can also calculate a competence score, problem score, and total score.

Both the summary scores (i.e., the competence, problem, and total scores) and the subscale scores are determined by calculating the mean for the appropriate items, with lower

scores equaling better functioning. Although there were some differences in subscale-factor loadings depending on whether the informant was the parent or the child, the three nearly identical factors that emerged from the parent and child data were labeled Task Performance, Sparetime Sociability, and Family Relations. These factors explained 24%, 14.7%, and 16.7% of the variance in the parent report, respectively. According to the child report data, each factor accounted for 16.7% of the variance in the SAICA Total Score. The above factor and variance results were determined by Gammon et al. (1987).

While denying the presence of gender effects, John, et al. (1987), did acknowledge some age effects. Specifically, they indicated that when compared to older children, children 11 years old and younger watched less television, were more involved with their fathers, and exhibited fewer problems with their parents. However, these younger children were said to demonstrate more peer difficulties than the adolescents. Although there was a relatively small normative sample and very few children in the 6 to 8 year old age

range, research suggests that the SAICA can successfully distinguish between children with and without Axis I pathology as well as between children with and without attention deficit disorder (John et al., 1987; Biederman, Faraone, & Chen, 1993). John et al. (1987) also reported high correlations between SAICA and CBCL items and subscales that are professed to assess similar content areas; these significant correlations imply relatively good concurrent validity between the SAICA and CBCL. In the current study, the SAICA Total Score will be used to indicate overall social adjustment.

The second dependent measure was The Child Behavior Checklist (CBCL). Developed by Achenbach (1991), the CBCL is an empirically derived, multi-axial questionnaire designed to screen for general psychopathology in children between 4 and 18 years of age. The measure consists of 20 social competence questions, 118 problem items, and two open-ended questions. The 20 social competence items cover the three areas of school performance, activities, and social involvement. The activities and social subscales assess both the

quality of contact as well as the level/amount of contact. The 118 problem items are separated into the eight subscales of withdrawn, anxious/depressed, social problems, somatic complaints, thought problems, attention problems, aggressive behavior, and delinquent behavior. These 8 subscales are then combined to result in internalizing, externalizing, and total problem scores (Drotar, et al. 1995). Frequently used in research and clinical practice, the CBCL norms are based on large samples (N=2368). In most circumstances, the CBCL is considered to yield both reliable and valid assessments of symptoms. However, Drotar et al. (1995) note that the CBCL's assessment of social competence and physical symptoms are potentially misleading (i.e., implying more difficulty than is actually the case), which is particularly problematic when used with ill children.

Because of the intention to use a combined SAICA/CBCL score as the primary measure of social adjustment, a scoring system was created for the CBCL to make it more analogous to the SAICA. This scoring system also made it easier to assess the concurrent validity of the SAICA to the CBCL. This

scoring method involved separating the Social Involvement area on the CBCL into the three areas of Peer Relations, Sibling Relations, and Relations with Parents. A CBCL Social Competence Score, which was adjusted for the number of items completed, was then developed to serve as a comparison measure for the SAICA Competence Score. Similarly, the mean for the CBCL problem items was calculated in order to serve as a comparison score for the SAICA Problem Score. In this study, the CBCL Social Competence Score can range from 0 to 1.9 while the CBCL Problem Score can range from 0 to 2; in both cases, lower scores represent better functioning. It should be noted that the above comparisons were the same as many of those conducted by John et al. (1987) in their analysis of the content similarity between the SAICA and CBCL.

Since the SAICA does not have separate norms based on age and gender, the modified CBCL scoring system did not include these variables. However, age and gender were included as covariates in the analyses involving the combined/joint SAICA/CBCL score. The SAICA and CBCL summary scores were transformed into z-scores prior to forming the Joint

Score, thus allowing one to compare the two measures despite differences in their original scales.

#### Social Anxiety Measure

The Social Anxiety Scale for Children-Revised (SASC-R) was an independent variable in some analyses and a dependent variable in other analyses. Developed by LaGreca and her colleagues, the SASC-R is a self-report questionnaire designed to assess social anxiety in children ages 6 to 12. However, the questions also appear to be appropriate for slightly younger children, assuming that they have contact with others. According to LaGreca and Stone (1993), the test is designed to measure the two components of social anxiety that Watson and Friend (1969) identified in adults, namely fear of negative evaluation from others (FNE) and deliberate avoidance of and distress in social situations (SAD). Taking less than 10 minutes to complete, the test was normed on children in the fourth through sixth grades. The Flesch-Kincaid formula revealed that SASC-R's reading ability has a grade equivalent of 2.5. Each of the test's 22-items (18 substantive and 4 filler) is scored on a Likert



scale ranging from 1 (hardly ever true) to 5 (true all the time). Subscale (i.e. Factor) scores are determined by finding the mean of the relevant items, with lower scores equaling better functioning. LaGreca and Stone (1993) note that the SASC-R is an improvement over its 10-item, 2-factor predecessor, the SASC, in terms of psychometric properties and in providing more extensive coverage of the SAD aspect of social anxiety. The three factors on the SASC-R are FNE (fear of negative evaluation from peers), SAD-New (social avoidance and distress in new situations or with unfamiliar peers), and SAD-General or SAD-G (generalized social avoidance and distress). These factors accounted for 68.9%, 13.1%, and 7.8% of the variance in the total SASC-R, respectively. The internal consistency for each subscale (i.e., Factor) as measured by Cronbach's coefficient alpha was .86 for FNE, .78 for SAD-New, and .69 for SAD-G.

LaGreca and Stone (1993) indicated the presence of gender and age effects. Specifically, younger children and girls obtained significantly higher SASC-R total scores and subscale scores than older children and boys. Indicating

that the SASC-R is able to differentiate among peer status groups, LaGreca and Stone (1993) suggest the use of the 3 factor scores rather than the total score. Sample size limitations necessitated using the SASC-R total score rather than the factor scores in analyses. However, all 3 factor scores as well as the total score were calculated.

#### Social Support Measure

Similar to the SASC-R, The Social Support Scale for Children (SSS) served as an independent variable in some analyses and a dependent variable in other analyses. Developed by Harter and her colleagues, the SSS is a self-report questionnaire designed to assess perceived social support received from significant others. Although initially intended for use with children 8 to 14, the measure also appears to be appropriate for younger school-aged children. Harter (1985) indicated that the SSS defines social support as the positive regard one gets from significant individuals in his/her life. Taking 10 to 15 minutes to complete, the questionnaire was normed on children in the third through eighth grades. Harter (1985) stated that the SSS can be

administered in either an individual or group format, with 5th graders and older being capable of reading the items to themselves. Scored from 1 to 4, each of the test's 24 items is presented in the structured alternative format described previously. The SSS consists of 4, 6-item subscales which are said to look at the four sources of social support identified by Harter and her colleagues; these four sources of social support are parents, teachers, classmates, and close friends. Harter (1985) acknowledged that other sources of support, such as siblings, may be important and should be assessed in certain situations by developing relevant items.

For elementary students (grades 3-6), the internal consistency coefficients for the subscales were .78 for the parent subscale, .74 for the classmate subscale, .82 for the teacher subscale, and .74 for the friend subscale, respectively. Harter (1985) indicated that they rewrote and reworded 4 of the friend items and 1 classmate item to try to improve the reliability of those subscales. She also stated that only 3 factors emerged for the elementary school students, with the friend and classmate subscales forming a

combined factor. Four factors, which generally correspond to the four subscales, emerged for middle school youth. Because many of the Cancer Group participants were unable to attend school, the Friend Scale score served as the measure of peer social support in the present study.

### Procedure

#### Participant Recruitment of the Cancer Group

Cancer Group participants included children with cancer who were medically followed at Shands Hospital. Potential participants were identified by reviewing the list of children scheduled for outpatient clinic visits at the Cancer Center or Brain Tumor Clinic. The remaining cancer participants were children admitted to the 9th floor at Shands Hospital, which includes pediatric oncology patients. For all children with cancer, nurses were first asked if the child was feeling well enough to answer some questions. Thereafter, the purpose and nature of the study were explained to the potential participant and his/her parent. Informed consent from the parent and assent from the child were then obtained (Appendices C and D).

### Participant Recruitment of the Control Group

The majority of healthy control participants were recruited in the summer of 1997 by contacting Summer Camps and Daycare Centers in Alachua County, where the Health Science Center is located, and providing them with a description of the study. Specifically, they were told that the investigator was interested in studying the social relationships of children 5 to 12 years of age. Directors of these programs were asked to send home a cover letter describing the study. Thereafter, parents were approached as they dropped off and picked up their children. Parents who had healthy children (in accordance with study criteria) and were willing to participate were given a packet containing study-related materials. The investigator also wrote down the parent's name and phone number to try to facilitate the return of parent measures as well as to set up a convenient time to speak with the child.

It should be noted that because of discrepancies in the age/gender combinations among the cancer and control participants, 20 additional control children were obtained in

late 1998 and early 1999 from medical establishments (i.e., a Pediatrician's office and Rehabilitation Hospital) located near the Health Center. The parents of these control participants were approached regarding the study while they were waiting for medical appointments or not occupied with job tasks. As with the previously collected controls, those parents who were willing to participate were given a packet containing study-related materials. Similarly, the investigator wrote down the parent's name and phone number to try to promote the return of parent measures as well as to set up a mutually agreeable time to speak with his/her child. For all control participants, parents provided verbal consent when the parent packets were handed out. See Appendix E for the Informed Consent form used for the Control Group.

Testing Procedures for the Cancer Group

The principal investigator or her research assistant requested that the parent fill out the Demographic Questionnaire, CBCL, and SAICA. Concurrently, the SASC-R and SSS were administered to the child. To avoid potential complications associated with poor reading skills, the measures

were read aloud to all children. The children were told that the examiner was interested in how children get along with other people, so she was asking children questions. They were informed that there were no right or wrong answers to the questions and that no one would know how he/she responded. Children were told they should ask questions about anything that was unclear. The research assistants were instructed to ask children if they knew the meaning of certain words, e.g., nervous and shy. If the child said no, then the examiner selected a synonym from a provided list to assist the child in answering the items. Children's questions took 10 to 15 minutes to complete.

Most parents finished their questions in less than 30 minutes. The majority of outpatient participants filled out the measures while they were at Shands Hospital for a clinic appointment. Due to time constraints, a few parents completed their forms at home and then mailed them to the investigator in a pre-stamped, addressed envelope. Inpatient participants completed the measures in either their room or in the common area on their floor at Shands Hospital.

Testing Procedures for the Control Group

A packet containing a cover letter, measure instructions/directions, written consent form, and three parent questionnaires was given to a parent of each control child. One parent was asked to fill out both the CBCL and SAICA to avoid interrater reliability issues. Either parent could complete the demographic questionnaire. In the cover letter, the examiner requested that the parent put the measures into the provided envelope and return them to the data collection site or directly to examiner through the University of Florida mail system. Parents were informed that a labeled box was located at the office of their recruitment site if the investigator was not present when they returned their questionnaires.

The child completed his/her two questionnaires during a time block that was convenient to the establishment where data was being collected (i.e., camps, daycare centers, and medical offices). Each child was seen individually for approximately 15 minutes. The measures were read aloud to all control subjects due to variability in reading skills. As



with the cancer participants, the control children were told that the examiner was interested in how children get along with other people, so she was asking children questions. They were informed that there were no right or wrong answers to the items and that no one would know his/her responses. Children were told they should ask questions about anything that was unclear. Likewise, the research assistants were told to use the synonym list if a child did not understand certain words.

#### Incentives and Confidentiality

All parents and children were told that none of the questionnaires had correct or incorrect responses. As an incentive to participate in the study, a \$2 gift certificate to a local movie theater or a coupon good for a free Happy Meal at McDonalds was made available to all child participants. Additional incentives for the Control Group were a chance to win a \$25 gift certificate to a restaurant or a \$10 movie pack. The winners of these rewards were randomly selected from those control participants whose parent and child data was complete. The restaurant certificate and one

movie pack were awarded to two families from the 1997 data collection group. Another movie pack was given to one family from the 1998-1999 study participants.

All of the participants were assigned a number in order to maintain their anonymity. Confidentiality was further insured by keeping the test materials in a locked office in the Health Science Center. Individuals taking part in the study were told that the principal investigator could be contacted if there were any questions.

## RESULTS

Information acquired from the interviews, medical record reviews, demographic questionnaires, medical questionnaires, and the administration of the remaining predictive and outcome measures was coded and entered into a database. Subsequently, SPSS for Windows was utilized to conduct the analyses in this study, which are described below.

### Demographic and Cancer Information

#### Demographic Information

The majority of demographic information was available for 175 participants and is presented in Table 4. The mean age for the entire sample was 8-years, 5-months. There were no significant differences between the Cancer and Control Groups ( $t(173)=-.76$ ,  $p=.446$ ) with respect to age at the time of assessment. In the Cancer Group, the average age of participants was 8-years, 4-months, with a range of 5-years, 0-months to 12-years, 9-months. In the Control Group, the average age of participants was 8-years, 7-months, with a

range of 5-years, 0-months to 12-years, 11-months. There were no significant differences between the two participant groups with respect to the distribution of males and females ( $\chi^2(1)=.01$ ,  $p=.917$ ). Boys comprised 55% of the Cancer Group and 55.8% of the Control Group.

Chi-square analyses revealed no significant differences between the Cancer and Control Groups in the distribution of all ethnicities ( $\chi^2(6)=7.525$ ,  $p=.275$ ), minorities and Caucasians ( $\chi^2(1)=.962$ ,  $p=.326$ ), or African-Americans and Caucasians ( $\chi^2(1)=4.627$ ,  $p=.099$ ). However, a review of the data does suggest that this trend towards different proportions of African-American and Caucasian children in the two participant groups primarily arises from the larger percentage of female African-American children in the Cancer Group (36.1%) relative to the Control Group (7.1%).

Various chi-square analyses indicated no significant differences between the Cancer and Control Groups with respect to family structure ( $\chi^2(4)=3.686$ ,  $p=.450$ ), family duration ( $\chi^2(3)=2.569$ ,  $p=.463$ ), or family size ( $\chi^2(4)=7.322$ ,  $p=.112$ ). In the majority of families, both the mother and

father were living in the home (Cancer Group=63.8%, Control Group=65.3%). The second most common family structure was households headed by single mothers (Cancer Group=22.5%, Control Group=23.2%). Most families had maintained their current parental composition for 5 or more years (Cancer Group=77.2%, Control Group=84.2%). Lastly, the majority of families had two or fewer children currently living at home (Cancer Group=58.75%, Control Group=76.85%).

Most children in both the Cancer (81.3%) and Control (96.8%) Groups were not receiving family-based federal assistance. However, chi-square analyses did reveal that significantly more Cancer Group families were receiving federal aid in comparison to Control Group families ( $\chi^2(1)=11.442$ ,  $p=.001$ ). These data suggest that the Cancer Group had more lower income families than the Control Group.

Mothers were the most common respondent to the questionnaires for both the Cancer Group (81%) and Control Group (80%). There were no significant differences in the adult informant between the groups ( $\chi^2(3)=1.354$ ,  $p=.716$ ). However, there were significant differences between the Cancer

and Control Groups with respect to the number of school or camp days missed in the month preceding data collection ( $t(170)=9.53$ ,  $p=.000$ ). This was expected given that 57.5% of the cancer participants were in the treatment phase of their diseases and treatment often necessitates frequent school absences due to medical appointments.

T-tests indicated that the parents of children in the Control Group had attained a significantly higher level of education than the parents of children in the Cancer Group (maternal education,  $t(169)=-3.78$ ,  $p=.000$ , paternal education,  $t(151)=-2.67$ ,  $p=.009$ ). However, it is noteworthy that at least a 12th grade education was typical for both mothers and fathers within both groups. Specifically, average maternal and paternal education were 13.39 and 13.91 years for the Cancer Group and 14.78 and 15.18 years for the Control Group, respectively.

#### Cancer Information

Three tables contain the cancer participants disease-related variables and child psychopathology data. Because research has occasionally revealed gender differences with

Table 4  
Demographic Information

<u>Variable</u>		<u>Entire</u> <u>Sample</u>	<u>Cancer</u> (n=80) <u>Boys</u>	<u>Girls</u>	<u>Entire</u> <u>Sample</u>	<u>Control</u> (n=95) <u>Boys</u>	<u>Girls</u>
<u>Age(years-months)</u>	<u>M and</u> <u>(SD)</u>	8-4 (2-4)	8-1 (2-4)	8-7 (2-3)	8-7 (2-3)	8-4 (2-3)	8-10 (2-3)
<u>Gender</u>	<u>n</u>	80	44	36	95	53	42
	<u>%</u>	100	55	45	100	55.8	44.2
<u>Ethnicity</u>							
<u>Caucasian</u>	<u>n</u>	59	39	20	76	43	33
	<u>%</u>	73.8	88.6	55.6	80	81.1	78.6
<u>African-American</u>	<u>n</u>	17	4	13	10	7	3
	<u>%</u>	21.2	9.1	36.1	10.5	13.2	7.1
<u>Other</u>	<u>n</u>	4	1	3	9	3	6
	<u>%</u>	5	2.3	8.3	9.5	5.7	14.3
<u>Family Structure</u>							
<u>Mom &amp; Dad</u>	<u>n</u>	51	28	23	62	36	26
	<u>%</u>	63.8	63.6	63.9	65.3	67.9	61.9
<u>Mom only</u>	<u>n</u>	18	11	7	22	14	8
	<u>%</u>	22.5	25	19.5	23.2	26.4	19.05
<u>Mom &amp; Stepdad</u>	<u>n</u>	8	5	3	11	3	8
	<u>%</u>	10	11.4	8.3	11.5	5.7	19.05

Table 4--continued

Variable		Entire Sample	Cancer (n=80) Boys	Girls	Entire Sample	Control (n=95) Boys	Girls
<u>Family Duration</u>							
<u>Always</u>	n	48	27	21	67	41	26
	%	60	61.4	58.3	70.5	77.4	61.9
<u>Over 5 years</u>	n	16	7	9	13	5	8
	%	20	15.8	25	13.7	9.4	19
<u>1 to 4 years</u>	n	9	5	4	10	6	4
	%	11.3	11.4	11.1	10.5	11.3	9.5
<u>less than 1 year</u>	n	7	5	2	5	1	4
	%	8.7	11.4	5.6	5.3	1.9	9.5
<u>Family Size</u>							
<u>1 or 2 Children</u>	n	47	24	23	73	42	31
	%	58.75	42.5	63.9	76.85	79.25	73.8
<u>3 or more Children</u>	n	33	20	13	22	11	11
	%	41.25	45.5	36.1	23.15	20.75	26.2
<u>Federal Aid</u> <u>Yes</u>	n	15	7	8	3	1	3
	%	18.7	15.9	22.2	3.2	1.9	4.8
<u>No</u>	n	65	37	28	92	52	40
	%	81.3	84.1	77.8	96.8	98.1	95.2



respect to disease and treatment characteristics, gender comparisons were computed for these variables. Table 5 has the categorical disease variables. There were no significant gender differences between male and female cancer participants with respect to disease type ( $\chi^2(1)=.914$ ,  $p=.339$ ), surgery ( $\chi^2(1)=.025$ ,  $p=.875$ ), bone marrow transplantation (BMT) ( $\chi^2(1)=.558$ ,  $p=.455$ ), disease-based physical/sensory changes ( $\chi^2(1)=.665$ ,  $p=.415$ ), school status ( $\chi^2(1)=.894$ ,  $p=.344$ ), or type of classroom ( $\chi^2(1)=1.27$ ,  $p=.26$ ). Specifically, the majority of children with cancer had non-CNS diseases (72.5%), had needed surgery (53.8%), had not undergone BMT (88.7%), and did not have permanent physical/sensory changes as a result of their illnesses (67.5%). Most children with cancer were attending school on a regular basis (61.3%) and were not receiving special education services (83.7%).

In contrast, there were some gender differences with respect to stage of illness ( $\chi^2(4)=7.028$ ,  $p=.134$ ), treatment status ( $\chi^2(1)=4.257$ ,  $p=.039$ ), disease status ( $\chi^2(1)=2.886$ ,  $p=.089$ ), chemotherapy ( $\chi^2(1)=5.657$ ,  $p=.017$ ), and radiation

( $\chi^2(1)=1.835$ ,  $p=.176$ ). Review of the stage of illness data revealed that a larger percentage of females than males had completed treatment (44.4% and 22.7%, respectively). In addition, more boys than girls were in the late (18.2% versus 11.1%) or stable (15.9% versus 2.8%) stages of their diseases. These gender-related stage of illness differences are further supported by the larger percentage of males than females who were currently receiving treatment or had residual treatment/disease effects at the time of data collection (77.3% and 55.6%, respectively). Although the majority of children had not relapsed (87.5%), recurrent disease was more common for males (18.2%) than females (5.6%). While most children had received chemotherapy (87.5%), chemotherapy was more frequently used with females (97.2%) than males (79.5%). Similarly, while radiation treatment was used with only 33.7% of the children with cancer, it was a more common treatment for females (41.7%) than males (13.6%). Lastly, formal psychological diagnoses were rare in the cancer sample (5%), with boys being the only gender with documented psychological disturbance (9.1% of males and 0% of females).

Table 5  
Categorical Disease Variables

<u>Variable</u>	<u>Entire Sample</u> (n=80)		<u>Boys</u> (n=80)		<u>Girls</u> (n=80)	
	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>
<u>Stage of Illness</u>						
<u>Early</u>	19	23.8	11	25	8	22.2
<u>Middle</u>	15	18.8	8	18.2	7	19.5
<u>Late</u>	12	15	8	18.2	4	11.1
<u>Post</u>	26	32.4	10	22.7	16	44.4
<u>Stable</u>	8	10	7	15.9	1	2.8
<u>Disease Status</u>						
<u>Initial</u>	70	87.5	36	81.8	34	94.4
<u>Recurrent</u>	10	12.5	8	18.2	2	5.6
<u>Disease Type</u>						
<u>Non-CNS Cancer</u>	58	72.5	30	68.2	28	77.8
<u>Brain Tumors</u>	22	27.5	14	31.8	8	22.2
<u>Disease-Related Physical Changes</u>						
<u>YES</u>	26	32.5	16	36.4	10	27.8
<u>NO</u>	54	67.5	28	63.6	26	72.2

Table 5--continued

<u>Variable</u>	<u>Entire Sample</u> (n=80)		<u>Boys</u> (n=80)		<u>Girls</u> (n=80)	
	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>
<u>Treatment Types</u>						
<u>Chemotherapy</u>	70	87.5	35	79.5	35	97.2
<u>Surgery</u>	43	53.8	24	54.5	19	52.8
<u>Radiation</u>	27	33.7	12	27.3	15	41.7
<u>BMT</u>	9	11.3	6	13.6	3	8.3
<u>Psychological Diagnosis</u>						
<u>YES</u>	4	5	4	9.1	0	0
<u>NO</u>	76	95	40	90.9	36	100
<u>School Status</u>						
<u>Regular</u>	49	61.3	29	65.9	20	55.6
<u>Homeschooling</u>	31	38.7	15	34.1	16	44.4
<u>Type of Classroom</u>						
<u>Regular</u>	67	83.7	35	79.5	32	88.9
<u>Special Ed.</u>	13	16.3	9	20.5	4	11.1

Table 6 contains the non-categorical disease variable data. There were no significant gender differences with respect to any of these non-categorical disease variables. The mean age at diagnosis was 5-years, 9-months, with approximately 2-years, 7-months having passed since they were first diagnosed. Illness duration, which assessed the typical length of time children had received treatment and/or had residual treatment effects, averaged 1-year, 5-months. On average, treatment had ceased 2-years, 9-months ago for the 34 children not currently on active treatment. Those patients presently receiving treatment had been doing so for 2-years. The majority of children had relatively few disease-related restrictions in social contact. The children had typically missed 9 of 20 or 45% of the school days during the month preceding data collection; this high rate of absenteeism is attributed to 48.75% of the children receiving some type of formal treatment at the time of data collection and, therefore, not attending school full time.

Table 6  
Non-Categorical Disease Variables

<u>Variable</u>	<u>Entire Sample</u>			<u>Boys</u>			<u>Girls</u>		
	<u>Mean</u>	<u>SD</u>	<u>Range</u>	<u>Mean</u>	<u>SD</u>	<u>Range</u>	<u>Mean</u>	<u>SD</u>	<u>Range</u>
<u>Age at Diagnosis</u> <sup>1</sup>	5-9	3-1	0 to 12-5 (n=80)	5-6	3-2	0 to 12-5 (n=44)	6-0	3-0	1-5 to 12-2 (n=36)
<u>Time Since Diagnosis</u>	2-7	2-5	0-1 to 12-7 (n=80)	2-6	2-5	0-1 to 12-7 (n=44)	2-7	2-5	0-1 to 7-0 (n=36)
<u>Illness Duration</u>	1-5	1-6	0-1 to 7-7 (n=80)	1-5	1-8	0-1 to 7-7 (n=44)	1-4	1-5	0-1 to 6-5 (n=36)
<u>Time Since Treatment Stopped</u>	2-9	1-9	0-3 to 8-0 (n=34)	3-1	2-10	0-3 to 8-0 (n=17)	2-4	1-6	0-3 to 5-10 (n=17)
<u>Time In Treatment</u>	2-0	2-6	0-1 to 9-11 (n=39)	1-11	2-6	0-1 to 9-11 (n=21)	2-1	2-5	0-2 to 8-4 (n=18)
<u>Social Restrictions Score</u>	6.66	1.55	4 to 8 (n=80)	6.7	1.41	4 to 8 (n=44)	6.61	1.69	4 to 8 (n=36)
<u>School Days Missed</u>	8.91	8.75	0 to 20 (n=7)	8.81	8.83	0 to 20 (n=42)	9.03	8.87	0 to 20 (n=35)

<sup>1</sup> Age and time periods are listed in months-years. For example, 10-3 equals 10 years and 3 months.

Lastly, the diagnosis information for the children with cancer is located in Table 7. As stated previously, the majority of pediatric oncology patients had non-CNS cancers (72.5%). The most frequent diagnosis was acute lymphocytic leukemia or ALL (33.8% of the sample), with 29.6% of the boys and 38.9% of the girls having this diagnosis. Medulloblastoma was the most prevalent CNS diagnosis, afflicting 22.7% of the children with brain tumors. It should be noted that the three children with Optic Glioma had developed their cancer secondary to Neurofibromatosis. None of the other children had physical disorders that were known to contribute to their development of cancer. Please refer to Table 7 for additional diagnosis information.

#### Measure Information

##### Descriptive Statistics

The means and standard deviations for the dependent variables and many of the independent variables are contained in Table 8. With the exception of the Friend Subscale of the SSS, lower scores represent better functioning. The Cancer and Control Groups were both within one standard

Table 7  
Diagnosis Information

<u>Diagnoses</u>	<u>Entire Sample</u> (n=80)		<u>Boys</u> (n=44)		<u>Girls</u> (n=36)	
	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>
<u>Non-CNS Diseases</u>	58	72.5	30	68.2	28	77.8
<u>ALL</u>	27	33.8	13	29.6	14	38.9
<u>Leukemia-Other</u>	5	6.2	4	9.1	1	2.8
<u>Neuroblastoma</u>	3	3.8	1	2.3	2	5.6
<u>Wilms Tumor</u>	4	5.0	0	0	4	11.1
<u>Lymphoma</u>	5	6.2	4	9.1	1	2.8
<u>Rhabdomyosarcoma</u>	6	7.5	3	6.8	3	8.2
<u>Bone Cancer</u>	6	7.5	3	6.8	3	8.2
<u>Malignancy-Other</u>	2	2.5	2	4.5	0	0
<u>Brain Tumors</u>	22	27.5	14	38.2	8	22.2
<u>Medulloblastoma</u>	5	6.2	3	6.8	2	5.6
<u>Brain Stem Glioma</u>	3	3.8	1	2.3	2	5.6
<u>Astrocytoma</u>	4	5.0	3	6.8	1	2.8
<u>Optic Glioma</u>	3	3.8	2	4.5	1	2.8
<u>Oligodendroglioma</u>	2	2.5	2	4.5	0	0
<u>Brain Tumor-Other</u>	5	6.2	3	6.8	2	5.6



deviation of test norms on the SAICA Total Score, SAICA Competence Score, SASC-R scores, and the SSS Friend Subscale score. The children in the Cancer Group obtained SASC-R subscale scores of 20.25 (SD=8.05) for FNE, 16.97 (SD=5.24) for SAD-New, and 9.48 (SD=3.43) for SAD-G. The healthy children obtained SASC-R subscale scores of 18.43 (SD=6.68) for FNE, 15.41 (SD=4.48) for SAD-New, and 8.20 (SD=2.84) for SAD-G. Boys in both groups were within one standard deviation of test norms on all of these measures. In contrast, there were two exceptions for female participants with respect to test norms. Specifically, girls in the Control Group scored approximately one-and-a-half standard deviations above test norms on the Friend subscale of the SSS, implying slightly above average social support from friends. Conversely, girls in the Cancer Group were about one-and-a-half standard deviations below test norms on the SAICA Total, suggesting slightly lower than average social adjustment. Please note that due to the creation of the CBCL scoring system and the Joint Score, no test norms were available for these two scores.

Table 8  
Descriptive Statistics

Measures	Cancer			Control			Possible Range of Scores
	entire sample	boys	girls	entire sample	boys	girls	
<u>Joint Score</u>	(n=78)	(n=43)	(n=35)	(n=93)	(n=52)	(n=41)	-3 to 3
<u>Range</u>	-1.89 to 2.57	-1.89 to 2.57	-1.36 to 1.83	-1.75 to 1.56	-1.60 to 1.56	-1.75 to 1.96	
<u>Mean</u>	.32	.25	.42	-.27	-.07	-.53	
<u>SD</u>	.93	1.02	.81	.76	.78	.66	
<u>SAICA Total Score</u>	(n=78)	(n=43)	(n=35)	(n=93)	(n=52)	(n=41)	1 to 4
<u>Range</u>	1.24 to 2.56	1.24 to 2.56	1.39 to 2.35	1.20 to 2.45	1.20 to 2.45	1.21 to 2.25	
<u>Mean</u>	1.80	1.78	1.82	1.68	1.76	1.59	
<u>SD</u>	.31	.33	.29	.27	.27	.25	
<u>SAICA Competence Score</u>	(n=78)	(n=43)	(n=35)	(n=93)	(n=52)	(n=41)	1 to 4
<u>Range</u>	1.17 to 2.77	1.17 to 2.48	1.27 to 2.77	1.10 to 2.53	1.10 to 2.44	1.17 to 2.53	
<u>Mean</u>	1.83	1.81	1.86	1.70	1.78	1.60	
<u>SD</u>	.35	.32	.38	.32	.30	.32	

Table 8--continued

<u>Measures</u>	<u>Cancer</u>			<u>Control</u>			<u>Possible Range of Scores</u>
	<u>entire sample</u>	<u>boys</u>	<u>girls</u>	<u>entire sample</u>	<u>boys</u>	<u>girls</u>	
<u>CBCL Competence Total</u>	(n=78)	(n=43)	(n=35)	(n=93)	(n=52)	(n=41)	0 to 1.9
<u>Range</u>	.23 to 1.41	.23 to 1.41	.44 to 1.32	.16 to 1.18	.29 to 1.18	.16 to 1.01	
<u>Mean</u>	.85	.83	.87	.65	.69	.61	
<u>SD</u>	.24	.25	.23	.21	.21	.19	
<u>SASC-R Total Score</u>	(n=79)	(n=44)	(n=34)	(n=95)	(n=53)	(n=42)	18 to 90
<u>Range</u>	18 to 76	18 to 75	28 to 76	18 to 70	22 to 70	18 to 67	
<u>Mean</u>	46.71	43.73	50.46	41.93	42.32	41.43	
<u>SD</u>	13.69	13.51	13.18	11.07	11.07	11.18	
<u>Friend Support Score</u>	(n=80)	(n=44)	(n=36)	(n=95)	(n=53)	(n=42)	1 to 4
<u>Range</u>	1.17 to 4	1.83 to 4	1.17 to 4	1 to 4	1 to 4	2.83 to 4	
<u>Mean</u>	3.27	3.25	3.30	3.58	3.48	3.70	
<u>SD</u>	.69	.68	.72	.47	.56	.29	

### Psychometric Data for the SAICA

The concurrent validity of the SAICA was assessed by calculating the correlation coefficients between the SAICA and the items covering similar content on the CBCL. These correlations are presented in Table 9. The range, mean, and standard deviation for the SAICA Total Score and CBCL Social Competence Score were also determined (see Table 8). For the Joint Score, all of the SAICA scores, the CBCL Social Competence Score, and the CBCL Problem Score, lower scores equal better functioning. In contrast, on the CBCL competence subscales (i.e., school, activity, peer, and parent areas), higher scores equal better functioning. Thus, positive correlations were expected among the Joint Score, SAICA Scores, CBCL Competence Score, and CBCL Problem Score while negative correlations were expected between the SAICA and CBCL subscale scores. Since the concurrent validity between the two measures was high, a composite score, that took into account responses on both the SAICA and CBCL, was developed. This composite score, which was named the Joint Score, was used as the measure of social functioning/social adjustment.

Table 9  
SAICA-CBCL Scale and Subscale Comparisons (n=171)

<u>Scales and Subscales</u>	<u>Correlation and P-Value</u>
<u>Joint Score &amp; SAICA Total Score</u>	.8896, p=.000
<u>Joint Score &amp; SAICA Competence Score</u>	.8008, p=.000
<u>Joint Score &amp; CBCL Competence Score</u>	.8896, p=.000
<u>SAICA &amp; CBCL Competence Scores</u>	.5537, p=.000
<u>SAICA &amp; CBCL Problem Scores</u>	.4947, p=.000
<u>SAICA &amp; CBCL School Scores</u>	-.3620, p=.000
<u>SAICA Sparetime Activity Score &amp; CBCL Activity Score</u>	-.1998, p=.009
<u>SAICA &amp; CBCL Peer Scores</u>	-.5063, p=.000
<u>SAICA &amp; CBCL Sibling Scores</u>	-.5294, p=.000
<u>SAICA &amp; CBCL Parent Scores</u>	-.2719, p=.000

### Comparisons Between the Cancer and Control Groups

A number of specific hypotheses were tested in this study. First, a multiple regression analysis with age and gender as the control variables, participant status (i.e., cancer versus control) as the independent variable, and the Joint Score as the dependent variable was performed to test Hypothesis 1, which contends that children with cancer would not significantly differ from healthy controls with respect to their social functioning. Contrary to the hypothesis, participant status was significantly related to the Joint Score,  $t(167)=4.572$ ,  $p=.000$ . This suggests that control children obtained significantly better social adjustment scores than children with cancer. The preceding analysis also tested Hypothesis 5, that social functioning increases with age, by looking at the significance of the age variable in terms of the sign of the slope relating the Joint Score to child age. Although in the hypothesized direction (i.e., as age increases, social functioning has a tendency to improve), this relationship did not reach a statistically significant level ( $t(167)=-1.039$ ,  $p=.3002$ ). Gender was not

significantly related to the Joint Score ( $t(167)=1.222$ ,  $p=.2234$ ). Overall, adjusted  $R^2$  indicates that the three independent variables of age, gender, and participant status accounted for 11% of the variability in the Joint Score.

Second, the social support portion of Hypothesis 4, which contends that children with cancer would report lower levels of social support from close friends (i.e., the SSS Friend Subscale Score) than healthy children, was tested by utilizing a multiple regression analysis with age and gender as the control variables and participant status as the independent variable. Participant status ( $t(171)=-3.36$ ,  $p=.001$ ) and age ( $t(171)=2.263$ ,  $p=.0249$ ) significantly predicted level of friend social support. These findings imply that control participants and older children perceived themselves as receiving significantly more social support from friends than cancer participants and younger children. Gender was not significantly associated with level of social support from close friends ( $t(171)=-1.341$ ,  $p=.182$ ). Overall, adjusted  $R^2$  indicates that 9% of the variability in the Friend

Subscale score of the SSS is attributable to the three independent variables of age, gender, and participant status.

Hypothesis 6, which claims that higher levels of friend support would be associated with better social functioning, was examined by a multiple regression analysis in which age and gender were the control variables, social support and participant status were the independent variables, and the Joint Score was the dependent variable. Both participant status ( $t(166)=3.931$ ,  $p=.000$ ) and level of friend support ( $t(166)=-2.253$ ,  $p=.026$ ) significantly predicted social adjustment. These findings suggest that control participants and youngsters with a higher level of friend support obtain significantly better social adjustment scores than children with cancer and youngsters with a lower level of friend support. Gender was not significantly associated with the social adjustment score ( $t(166)=1.046$ ,  $p=.2970$ ). Overall, adjusted  $R^2$  revealed that 13% of the variability in the Joint Score was accounted for by the four independent variables of age, gender, participant status, and level of social support from close friends.



Next, the hypotheses related to social anxiety were tested. A multiple regression analysis containing the independent variables of age, gender, and participant status and the dependent variable of social anxiety (i.e., the SASC-R Total Score) was used to examine part of Hypothesis 4 and Hypothesis 7. Specifically, this analysis looked at the assertions that cancer participants, younger children, and girls would have greater social anxiety than control participants, older children, and boys. Participant status ( $t(170)=2.452$ ,  $p=.015$ ) and child age ( $t(170)=-3.283$ ,  $p=.001$ ) were significantly associated with social anxiety. These findings indicate that older children and healthy youth report significantly less social anxiety than younger children and youth with cancer. Additionally, as predicted, there was a trend for girls to report a higher level of social anxiety than boys ( $t(170)=-1.790$ ,  $p=.075$ ). Adjusted  $R^2$  suggests that the three independent variables of age, gender, and participant status accounted for 9% of the variability in the SASC-R Score.

Lastly, a multiple regression analysis with age and gender as the control variables, participant status and social anxiety as the independent variables, and social adjustment as the dependent variable was used to test Hypothesis 8, which contends that children who report lower levels of social anxiety would have better social functioning than those children who report higher levels of social anxiety. Both participant status ( $t(165)=4.101$ ,  $p=.000$ ) and social anxiety ( $t(165)=2.348$ ,  $p=.02$ ) were significantly related to social adjustment. These results imply that healthy children and youth with lower levels of social anxiety obtain significantly better social adjustment scores than children with cancer and youth with higher levels of social anxiety. Gender ( $t(165)=1.466$ ,  $p=.144$ ) and age ( $t(165)=-.473$ ,  $p=.6370$ ) did not significantly predict social adjustment. Overall, adjusted  $R^2$  indicates that 14% of the variability in the Joint Score was associated with the independent variables of age, gender, participant status, and social anxiety.

### Comparisons Within the Cancer Group

Several analyses involving only Cancer Group participants were conducted. The hypotheses involving many of the cancer participants' disease variables (i.e., Hypotheses 2a-2d) were examined by a (2)X(2)X(2) between groups analysis of covariance. Independent variables consisted of treatment status (off treatment versus currently on treatment and/or residual treatment/disease effects), disease type (cancers that do not primarily involve the CNS versus brain tumors or CNS disease), and disease status (initial disease diagnosis versus recurrent disease). It was hypothesized that children who were off treatment, had non-CNS disease, and had non-recurrent illness would obtain the best social functioning scores, as measured by the Joint Score. Covariates were gender, age, and degree of illness-related restrictions in social contact. After adjustment by the covariates, there were no significant main effects or interactions for any of the independent variables. However, the main effect for disease type was in the hypothesized direction,  $F_{(1,71)}=1.78$ ,  $p=.186$ , with a tendency for children with CNS diseases/brain

tumors (Joint Score mean=.5074) to do have worse social adjustment than children with non-CNS diseases (Joint Score mean=.2578). In addition, the partial correlation between the social restrictions score and the Joint Score (partial  $r=-.156$ ,  $p=.175$ ) suggests that as illness-related restrictions in social contact decrease or lessen, social functioning has a slight tendency to improve. Also, as predicted, those children who were still receiving treatment and/or had residual disease or treatment effects had significantly more disease-related restrictions in their social contact than those children who had completed treatment ( $t(78)=-5.82$ ,  $p=.000$ ). Therefore, while there were some trends in the expected directions, none of the hypotheses relating disease variables to social adjustment were statistically significant when the entire Cancer Group was included in the analysis. Unfortunately, Hypothesis 3, which asserted that youth with psychological diagnoses would do worse socially than youth without psychological diagnoses, could not be tested due to the fact that only 5% of the children with cancer had formally diagnosed psychological disturbances.

One stepwise multiple regression analysis that included all cancer participants was performed. The potential predictive variables in this analysis were age, age at diagnosis, gender, treatment status, disease status, disease type, disease-related sensory/physical changes, illness duration, disease-related restrictions in social contact, social anxiety, and social support from close friends. The dependent variable was the Joint Score. Interestingly, this analysis revealed that the only statistically significant predictor of the Joint Score was level of friend social support, with  $t(75) = -3.287$ ,  $p = .002$ . This suggests that children with cancer who report higher levels of friend support obtain significantly better social adjustment scores than those who report lower levels of friend support. While not significantly related to the Joint Score, social anxiety ( $t(75) = 1.752$ ,  $p = .084$ ) did show a trend, with a higher level of social anxiety being associated with worse social adjustment. Adjusted  $R^2$  indicates that 11% of the variability in the Joint Score was attributable to the level of social support that children with cancer receive from close friends.

A forward selection logistic regression was also conducted. The dependent measure in this analysis was the Joint Score, but only those children who scored in the top third (poor adjustment) or bottom third (good adjustment) on the Joint Score were included in this analysis. Twenty-five children with cancer or 31.25% of the Cancer Group met the criteria for inclusion in the logistic regression. Please note that the computer recoded children with poor social adjustment as zero (n=14) and children with good social adjustment as one (n=11), resulting in the signs for the independent variables being in the opposite direction from previous analyses in which the Joint Score was the dependent measure. The potential predictive variables in this analysis were the same as those used in the stepwise cancer participant regression analysis with the exception of disease status. The disease status variable had to be excluded from this logistic regression analysis because only 1 of the 25 children had a recurrent cancer. The chi-square for this logistic regression equation was statistically significant, which indicates a good fit between the observed and expected

frequencies generated by the model. The variables that significantly differentiated well adjusted from poorly adjusted children with cancer were level of social support from close friends ( $b=3.933$ ,  $p=.033$ ) and disease-related restrictions in social contact ( $b=2.175$ ,  $p=.036$ ), with social anxiety ( $b=.2$ ,  $p=.077$ ) and treatment status ( $b=-3.184$ ,  $p=.08$ ) approaching significance. All other potential predictor variables did not significantly increase chi-square if they were added to the model. These findings suggest that pediatric oncology patients tend to do worse socially if they have less social support from close friends, a relatively high degree of disease-related restrictions in social contact, more social anxiety, and are currently receiving treatment and/or have residual disease or treatment effects.

## DISCUSSION

The primary objective of the present study was to investigate, and hopefully elucidate, the relationships among various individual characteristics, disease characteristics, psychological variables, and the overall social adjustment of pediatric oncology patients. To achieve this goal, 80 school-aged children with cancer were assessed by having parents, medical respondents, and children respond to several questionnaires. In addition, healthy children served as a comparison group. The inclusion of the healthy controls allowed the investigators to examine whether children with cancer differed from healthy youth in their levels of social functioning, social anxiety, and social support from peers.

First, findings indicated that with a few exceptions, namely statistically higher socioeconomic status and parental education in the Control Group relative to the Cancer Group, there were no significant differences between the two groups of participants with respect to demographic characteristics (e.g., age, gender, ethnicity, and family variables). In



contrast, there were statistically significant differences between the Cancer and Control Groups in the levels of social adjustment, social anxiety, and social support received from close friends, with the healthy children demonstrating superior functioning when compared to the oncology children. However, as noted in the descriptive statistics portion of the results section, both groups of children were within one standard deviation of test norms on the various measures. These findings suggest that although their scores were below those of the healthy controls, the children with cancer did tend to function within normal limits with respect to social functioning, social anxiety, and level of social support from peers.

Other researchers have found similar results. Specifically, children with cancer occasionally perform worse than healthy controls on measures of adjustment, yet the oncology patients' scores still fall within the normal range of functioning (Kupst, 1994; Morris et al. 1997). These differences between healthy children and those with cancer on psychological measures may arise from subclinical difficulties within the pediatric cancer population (Adamoli et al. 1997; Drotar

et al. 1995; Hill et al. 1998; Kupst, 1994). As noted by Drottar et al. (1995), these subclinical problems warrant investigation since they could develop into more significant issues as the child and his or her family combat the stressors inherent to cancer and its treatment.

Although the analyses suggested that social adjustment often improved with age, this age-adjustment association did not reach a statistically significant level. The fact that a much larger portion of the participants were at the beginning versus the end of the age span (i.e., many more 5-and-6-year-olds than 11-and-12-year-olds) and the relatively small age range (i.e., ages 5 to 12) made it more difficult to detect age-related differences in social functioning due to decreased power. The tendency for younger children to have more adjustment issues when compared to older children is consistent with some of the previous pediatric oncology literature (Kupst et al. 1995; Sawyer et al. 1995).

As predicted, children who reported higher levels of social anxiety received worse social adjustment ratings from their parents than children who relayed lower levels of social

anxiety. In addition, younger youth reported significantly more social anxiety than older youth and girls had a slight tendency to report more social anxiety than boys. The presence of age and gender effects with respect to social anxiety is consistent with the work of LaGreca and Stone (1993).

Level of social support from friends also had a significant relationship to adjustment, with higher levels of social support being positively correlated with better social functioning. The observed associations between social adjustment and both social anxiety and friend social support are not surprising given that relationships with others, such as friends and peers, are a primary source of children's social knowledge, social skills, and social competence (Furman & Robbins, 1985; Hartup, 1989). Consequently, if children are having difficulty in their social relationships (e.g., minimal social support from friends and anxiety in social situations), they are also likely to demonstrate difficulties in social adjustment. Research by Varni et al. (1994) and Varni et al. (1993) has found support for this link between the quality of relationships and overall adjustment within the pediatric oncology

population. Specifically, children with cancer who had low levels of anxiety and high levels of social support were found to have less psychological distress, fewer behavior problems, and better school competence than those patients with high levels of anxiety and low levels of social support.

Two regression analyses were conducted solely with the cancer participants, thus allowing for the inclusion of illness variables. Within the Cancer Group, several variables were related to parental ratings of child social adjustment. Social support from friends had the strongest association to social adjustment, with higher levels of support being positively associated with better social functioning. In fact, friend social support was the only variable that reached statistical significance in predicting social adjustment when the entire Cancer Group was included in the analysis. Social support from friends was also a statistically significant predictor of social adjustment when well versus poorly adjusted cancer participants were compared.

Social anxiety was a moderately strong predictor of social adjustment in both of the cancer participant regression

analyses. In fact, social anxiety became a statistically significant predictor of social adjustment when the analysis was limited to children at the extremes of the social adjustment spectrum (i.e., those with good or poor adjustment). Specifically, there was a strong trend for children with cancer who relayed relatively high levels of social anxiety to obtain relatively poor social adjustment scores when compared to those who reported relatively lower levels of social anxiety.

The five stage of illness categories failed to have a statistically significant relationship to social adjustment. This lack of a strong association between stage of illness and social functioning is partly attributable to the relatively small number of children in each stage of illness category, which decreased power and, thereby, the ability to detect differences between conditions/stages of illness. However, when children with good and poor adjustment were compared, those children with cancer who were either earlier in the treatment process or had residual disease/treatment effects had a tendency for decreased social functioning relative to those children who had completed treatment without adverse sequelae.

Additionally, illness based restrictions in social contact are related to stage of illness since those who are off treatment are likely to have fewer illness-based social constraints than those on treatment. As expected, illness-related restrictions in social contact significantly differentiated between well and poorly adjusted children with cancer, with higher rates of illness-related social constraints being positively correlated with worse adjustment.

Although it did not reach statistical significance, disease type did demonstrate a slight trend, with children who had brain tumors typically receiving lower social adjustment ratings than those children who had non-CNS diseases. As with the stage of illness variable, the relatively small number of children with brain tumors in the sample resulted in lower power and decreased the likelihood of detecting potential differences in adjustment based on disease type.

The present study and previous research suggest that a number of variables should be incorporated into the evaluation process when trying to determine which pediatric oncology patients are in the most need of intensive social intervention.

These variables include: (1) the number and quality of friendships and peer relationships, (2) the extent of social isolation and social anxiety, (3) the level of physical and/or sensory impairment, (4) the type of disease (i.e., CNS versus non-CNS cancer), (5) the treatment methods used, and (6) the age of the child (Adamoli, et al. 1997; DeRosier, et al. 1994; Hill et al., 1998; Hymel et al. 1990; Kupersmidt & Patterson, 1991; Kupst, 1994; Noll et al. 1990; Noll et al. 1993; O'Neil et al. 1997; Pendley et al. 1991; Radcliffe et al. 1996; Rowland, 1989; Sawyer et al. 1995; Spirito et al. 1990; Taylor, 1989; Vannatta, et al. 1998a; Vannatta et al. 1998b; Webster-Stratton & Lindsay, 1999).

Children with cancer who present with several of the following characteristics seem to be at a relatively high risk for social maladjustment: (1) few close friends, (2) high levels of aggression and limited prosocial skills, (3) a high level of social anxiety, (4) sensory and/or physical impairment, (5) CNS disease/brain tumor, (6) treatment with cranial radiation, and (7) young in age. In addition, diagnosis and the beginning of treatment are often a highly

stressful period of time for pediatric oncology patients and their families. This stress is intensified by the fact that the child is frequently restricted in his or her regular activities and social contact with others due to immunological concerns (Baum & Baum, 1989; Cincotta, 1993; Rowland; 1989). Consequently, social adjustment screening should be conducted relatively early on in the treatment process (Sawyer et al. 1995; Sawyer et al. 1998; Varni & Katz, 1987). However, periodic reevaluation of social adjustment is also strongly recommended given that cancer and its treatment involve frequent readjustment and new challenges in accordance with the child's disease and treatment course (Baum & Baum, 1989; Cincotta, 1993; Noll & Kazak, 1997).

A number of limitations exist in this study. First, as is common in many studies involving children with cancer, the cancer participants were all attending the same hospital. Using only one health system decreases generalizability since it is difficult to determine if the results are center specific or if they are a reasonable approximation of the functioning of children with cancer who receive their treatment at other



institutions. Secondly, to promote healthy child recruitment, the control participants were obtained from the city in which the health center that serves the cancer participants is located rather than the cancer participants' own communities. While there were very few significant differences between the Cancer and Control Groups with respect to demographic data, there is no way to be certain that geography did not influence test findings.

A third problem was the relatively small number of participants in each group, which restricted the ability to perform within group comparisons. As noted previously, this sample size issue resulted in decreased power, which made it more difficult to examine hypotheses related to many of the disease variables as well as possible developmental questions. The relatively small number of participants within each group also compromised the generalizability of the results since each child was weighted relatively strongly in the analyses. This may have lead to the inflation of some findings as well as the failure to detect others.

A fourth problem was that the SAICA was somewhat difficult to administer properly because parents often failed to answer questions correctly despite the provision of written instructions and examples. Therefore, to obtain useable data, the SAICA appears to necessitate more direct contact with families than other self-report measures. Given that there were few misinterpretations of the CBCL, it seems as if the CBCL is preferable to the SAICA if there is a low probability of direct contact with respondents during questionnaire completion.

When the findings of the current investigation are considered within the context of previous studies, there are several ramifications with regard to future research. First, it is important to formally assess family variables, such as parental stress and characteristics of the family environment, when examining social functioning in pediatric cancer patients given that such variables have been found to be related to adjustment in several studies (Brown et al. 1992; Kupst et al. 1995; Morris et al. 1997; Sawyer et al. 1998). Secondly, conducting research at several sites could help counteract sample

size limitations, improve the ability to examine developmental issues, and increase the generalizability of study results (Armstrong, 1995; Drotar, 1994; Sawyer et al. 1995).

Thirdly, there is a strong need for longitudinal studies in all areas of pediatric psychology, including pediatric oncology (LaGreca, 1990; Michael & Copeland, 1987; Varni & Katz, 1987; Wallander & Thompson, 1995). Black and Holden (1995) point out that the advantages of longitudinal studies include: (1) better consideration of developmental issues and intraindividual factors, and (2) the ability to look at the consistency of functioning across time. With regard to social functioning, longitudinal studies would enable researchers to see which children with cancer maintain their premorbid level of social adjustment and which show variation in their social functioning (i.e., who demonstrates improvement or decline in adjustment relative to earlier assessments). Thereafter, such information could be used to target children who seem to have a relatively high risk for experiencing difficulties in their social functioning.

The quality of friendships is a fourth area that should be included in social functioning studies given that there is a strong connection between friendships, overall peer relationships, and both short and long-term adjustment (Asher & Parker, 1987; Coie & Cillessen, 1993; Spirito et al. 1991). In particular, in accordance with the Disability-Stress Coping Model, the ability of friendships to provide a sense of intimacy, affection, and companionship may help serve as a buffer or resistance factor against the stressors associated with chronic illnesses such as cancer (Varni et al. 1994; Wallander & Thompson, 1995).

Multiple methods of assessing social functioning, such as adult and child report, sociometric ratings, and behavioral observation are also desirable. Using methods in addition to parent or child self-report can help clarify the accuracy and validity of both parent and child responses to questionnaires. In addition, observations of behavior and peer perceptions of the target child can also provide suggestions regarding behaviors that could benefit from intervention (Bierman & Montminy, 1993; Foster et al. 1993; Oglivvy, 1993; Newcomb et al. 1993).

Lastly, children in the various low peer status groups have been found to have deficits in their social information processing skills (Brochin & Wasik, 1992; Dodge & Price, 1994; Erwin, 1994; Kurdek & Krile, 1982; Mott & Krane, 1994). Inclusion of social information processing measures when assessing pediatric oncology patients would assist researchers in determining if children with cancer differ from healthy youth in their social information processing abilities. In addition, they could also explore the possibility that children with cancer who have poor social adjustment may demonstrate social information processing deficits relative to pediatric oncology patients who have good social functioning. If social information processing deficits are detected, techniques that have shown promise in increasing these abilities, such as social skills training, could be added to social intervention models.

As mentioned in the introduction, cancer and its treatment have a high probability of having a negative impact on the social adjustment of children due to their numerous adverse effects on both physical functioning and the ability of

children to engage in their typical, routine activities of daily life (LaGreca, 1990). Research has consistently indicated that social functioning in childhood is strongly connected to psychological health and adjustment throughout the life-span (Coie & Cillessen, 1993; LaGreca, 1990; Parker & Asher, 1987; Spirito et al. 1991). Since financial resources are usually limited, it is vital to determine which children with cancer require the more intensive, and likely more expensive, social interventions. Additionally, it is necessary to develop more social interventions which specifically address areas of social functioning that are particularly susceptible to the influence of disease variables. The social skills program of Katz and Varni (1993) is a good example of this desired type of social intervention.

As noted previously, both the present as well as past investigations reveal that several individual, disease, and psychosocial characteristics should be assessed when deciding who should be selected to participate in the various treatment options designed to enhance social functioning. The objective of promoting the social adjustment and social competence of

pediatric oncology patients has the best likelihood of being attained if the various characteristics described earlier, such as level of support from friends, social anxiety, constraints in social contact and disease/treatment status, are incorporated into the screening assessment process of social intervention programs. By assisting children with cancer in achieving adequate social functioning, most clinicians are closer to realizing their ultimate goal for pediatric oncology patients, namely a satisfying and acceptable quality of life.

#### APPENDIX A-DEMOGRAPHIC QUESTIONNAIRE

Your child is participating in a study designed to assess social functioning in youth. To assist us in this study, please provide the following information. Thanks.

#### CHILD INFORMATION

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Gender:      male              female      Grade in School: \_\_\_\_\_

Ethnicity (circle one):    White      Black      Hispanic      Asian

Native American      East Indian      Other

Has your child ever been diagnosed with a psychiatric or psychological disorder? NO YES (please specify) \_\_\_\_\_.

Does your child have any chronic pediatric illnesses or conditions? NO YES (please specify) \_\_\_\_\_.

Has the above illness resulted in any permanent physical changes, such as loss of vision, hearing or limb usage?  
NO YES (please specify) \_\_\_\_\_.

How many days of school has your child missed during the past month? \_\_\_\_\_.



Is your child enrolled in any special classes at school?

NO YES. If yes, please specify and describe subject areas:

Title 1 \_\_\_\_\_ Chapter 1 \_\_\_\_\_ Slow Learners \_\_\_\_\_

Is your child homeschooled? NO YES. If yes, please specify reason (circle one):

medical      parental choice      other (please describe) \_\_\_\_\_

**PARENT INFORMATION**

**MOTHER** (\_\_\_ check here if not applicable)

Age: \_\_\_\_\_ Highest Grade Completed \_\_\_\_\_

Ethnicity (circle one): White      Black      Hispanic

Asian      Native American      East Indian      Other

**FATHER** (\_\_\_ check here if not applicable)

Age: \_\_\_\_\_ Highest Grade Completed \_\_\_\_\_

Ethnicity (circle one): White      Black      Hispanic

Asian      Native American      East Indian      Other

Does your family currently receive federal assistance?

NO YES. If yes, please circle type:

child      family      other (please describe) \_\_\_\_\_

What adults currently live in the home (circle one):

mother and father      mother only      father only

mother and stepfather    father and stepmother    other (please describe) \_\_\_\_\_

Please list the gender and ages of all children in the home.

\_\_\_\_\_.

How long has the current family structure been in existence?

(circle one):    always    over 5 years    less than 1 year

other (please describe) \_\_\_\_\_

APPENDIX B-CANCER QUESTIONNAIRE

SECTION A: (will be completed by examiner)

Child Name: \_\_\_\_\_ Date: \_\_\_\_\_

Protocol Number: \_\_\_\_\_ Week of Treatment: \_\_\_\_\_

Diagnosis: \_\_\_\_\_ Oncologist/Neurologist: \_\_\_\_\_

Date of Diagnosis: \_\_\_\_\_ Illness Duration (in months): \_\_\_\_\_

Stage of Illness: early middle late post stable

Disease Status: initial diagnosis disease recurrence

Treatment Types: (circle all that apply)

(1) chemotherapy-YES NO

(2) radiation YES NO

(3) bone marrow transplantation YES NO

(4) surgery (describe) \_\_\_\_\_

Location: Cancer Center Brain Tumor Clinic Inpatient Unit

SECTION B: Given the child's diagnosis and treatment regimen, please use your best judgment in answering the following questions regarding the extent to which the child listed above is restricted in his/her opportunities for social contact due to:

- (1) disease-related physical changes (e.g., loss of mobility  
or sensory functioning) YES NO
- (2) compromised immunological status limiting:
- (a) social interactions outside the home (e.g. visiting  
with peers) YES NO
- (b) access to public facilities (e.g. malls/parks) YES NO
- (c) school attendance YES NO

APPENDIX C-INFORMED CONSENT FOR NON-CNS CANCER PARTICIPANTS

*Informed Consent to Participate in Research*

The University of Florida

Health Science Center

Gainesville, Florida 32610

You are being invited to participate in a research study. This form is designed to provide you with information about this study. The Principal Investigator or representative will describe this study to you and answer any of your questions. If you have any questions or complaints about the informed consent process or the research study, please contact the Institutional Review Board (IRB), the committee that protects human subjects, at (352) 846-1494.

1. Name of Subject

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2. Title of Research Study

-Social Adjustment in Children with Cancer

3. a. **Principal Investigator(s) and Telephone Number(s)**

Wendy Kubar, M.S. 395-0294

Eileen Fennell, Ph.D. 395-0680 ext. 5-4580

b. **Sponsor of the Study (if any)**

4. **The Purpose of the Research**

-This study will try to learn about how a child's age, sex, and health are related to how he or she gets along with others. This information can then be used to develop methods to help children with cancer who may have difficulties interacting with others.

5. **Procedures for This Research**

-You will be asked to fill out three questionnaires while your child will complete his or her two questionnaires. The items will be read aloud to your child by the examiner. It will take about a half hour to complete these forms.

6. **Potential Health Risks or Discomforts**

-There are no known potential health risks or discomforts.

If you wish to discuss these or any other discomforts you may experience, you may call the Principal Investigator listed in #3 on this form.

**7. Potential Health Benefits to You or to Others**

-There are no direct health benefits to you or your child. However, this study hopes to identify how the age, sex, and health of children may increase the chance of having problems in getting along with others. This information could lead to future methods to help lessen for social difficulties in children with cancer.

**8. Potential Financial Risks**

-There are no potential financial risks to study participation.

**9. Potential Financial Benefits to You or to Others**

-Your child will have the choice of either a movie pass or gift certificate to a fast food restaurant for participating in this study.

**10. Compensation for Research Related Injury**

In the unlikely event of you sustaining a physical or psychological injury which is proximately caused by this study: \_\_\_\_ professional medical; or \_\_\_\_ professional dental; or X professional consultative care received at the University of Florida Health Science Center will be provided without charge. However, hospital expenses will have to be paid by you or your insurance provider. You will not have to pay hospital expenses if you are being treated at the Veterans Administration Medical Center (VAMC) and sustain any physical injury during participation in VAMC-approved studies.

**11. Conflict of Interest**

-There is no conflict of interest associated with study participation.

**12. Alternatives to Participating in this Research Study**

You are free not to participate in this study. If you choose to participate, you are free to withdraw your consent and discontinue participation in this research study at any time without this decision affecting your medical care. If



you have any question regarding your rights as a subject, you may phone the Institutional Review Board (IRB) office at (352) 846-1494.

### **13. Withdrawal From this Research Study**

-If you wish to stop your participation in this research study for any reason, you should contact Wendy Kubar, M.S. at 395-0294. You may also contact the Institutional Review Board (IRB) Office at (352) 846-1494.

### **14. Confidentiality**

The University of Florida and the Veterans Administration Medical Center will protect the confidentiality of your records to the extent provided by Law. You understand that the Study Sponsor, Food and Drug Administration and the Institutional Review Board have the legal right to review your records.

-Confidentiality will be maintained by using assigned numbers rather than you or your child's name. All questionnaires will be kept in a locked office in the Health Science Center.

**15. Assent Procedure (if applicable):** [Assent is the procedure used to obtain agreement to participate in the research from a subject, such as a child, who cannot give legal consent]

-Your child will be told that the researcher is interested in how children get along with each other. He or she will also be told that to study children's peer relations, the researcher/assistant will need to ask him/her some questions. If your child participates in our study, he or she will get to choose a reward (i.e., the gift certificate or movie pass described above).

**16. Signatures**

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Subject's Name

The Principal or Co-Principal Investigator or representative has explained the nature and purpose of the above-described procedure and the benefits and risks that are involved in this research protocol.

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Signature of Principal or Co-Principal                      Date

Investigator or representative obtaining consent

You have been informed of the above-described procedure with its possible benefits and risks and you have received a copy of this description. You have given permission for your participation in this study.

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Signature of Subject or Representative                      Date

If you are not the subject, please print your name \_\_\_\_\_

and indicate one of the following:

- \_\_\_\_\_ The subject's parent
- \_\_\_\_\_ The subject's guardian
- \_\_\_\_\_ A surrogate
- \_\_\_\_\_ A durable power of attorney
- \_\_\_\_\_ A proxy
- \_\_\_\_\_ Other, please explain:

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Signature of Witness

Date

If a representative signs and if appropriate, the subject of this research should indicate assent by signing below.

---

Subject's signature

Date

APPENDIX D-INFORMED CONSENT FOR CNS CANCER PARTICIPANTS

*Informed Consent to Participate in Research*

The University of Florida

Health Science Center

Gainesville, Florida 32610

You are being invited to participate in a research study. This form is designed to provide you with information about this study. The Principal Investigator or representative will describe this study to you and answer any of your questions. If you have any questions or complaints about the informed consent process or the research study, please contact the Institutional Review Board (IRB), the committee that protects human subjects, at (352) 846-1494.

1. Name of Subject

---

2. Title of Research Study

-Social Adjustment in Ill Children

3. a. **Principal Investigator(s) and Telephone Number(s)**

Wendy Kubar, M.S. 395-0294

Eileen Fennell, Ph.D. 395-0680 ext. 5-4580

b. **Sponsor of the Study (if any)**

4. **The Purpose of the Research**

-This study will try to learn about how a child's age, sex, and health are related to how he or she gets along with others. This information can then be used to develop methods to help children with brain tumors who may have difficulties interacting with others.

5. **Procedures for This Research**

-You will be asked to fill out three questionnaires while your child will complete his or her two questionnaires. The items will be read aloud to your child by the examiner. It will take about a half hour to complete these forms.

6. **Potential Health Risks or Discomforts**

-There are no known potential health risks or discomforts.

If you wish to discuss these or any other discomforts you may experience, you may call the Principal Investigator listed in #3 of this form.

**7. Potential Health Benefits to You or to Others**

-There are no direct health benefits to you or your child. However, this study hopes to identify how the age, sex, and health of children may increase the chance of having problems in getting along with others. This information could lead to future methods to help lessen for social difficulties in children with brain tumors.

**8. Potential Financial Risks**

-There are no potential financial risks to study participation.

**9. Potential Financial Benefits to You or to Others**

-Your child will have the choice of either a movie pass or gift certificate to a fast food restaurant for participating in this study.

**10. Compensation for Research Related Injury**

In the unlikely event of you sustaining a physical or psychological injury which is proximately caused by this study: \_\_\_\_ professional medical; or \_\_\_\_ professional dental; or X professional consultative care received at the University of Florida Health Science Center will be provided without charge. However, hospital expenses will have to be paid by you or your insurance provider. You will not have to pay hospital expenses if you are being treated at the Veterans Administration Medical Center (VAMC) and sustain any physical injury during participation in VAMC-approved studies.

**11. Conflict of Interest**

-There is no conflict of interest associated with study participation.

**12. Alternatives to Participating in this Research Study**

You are free not to participate in this study. If you choose to participate, you are free to withdraw your consent and discontinue participation in this research study at any time without this decision affecting your medical care. If



you have any question regarding your rights as a subject, you may phone the Institutional Review Board (IRB) office at (352) 846-1494.

### **13. Withdrawal From this Research Study**

-If you wish to stop your participation in this research study for any reason, you should contact Wendy Kubar, M.S. at 395-0294. You may also contact the Institutional Review Board (IRB) Office at (352) 846-1494.

### **14. Confidentiality**

The University of Florida and the Veterans Administration Medical Center will protect the confidentiality of your records to the extent provided by Law. You understand that the Study Sponsor, Food and Drug Administration and the Institutional Review Board have the legal right to review your records.

-Confidentiality will be maintained by using assigned numbers rather than you or your child's name. All questionnaires will be kept in a locked office in the Health Science Center.

**15. Assent Procedure (if applicable):** [Assent is the procedure used to obtain agreement to participate in the research from a subject, such as a child, who cannot give legal consent]

-Your child will be told that the researcher is interested in how children get along with each other. He or she will also be told that to study children's peer relations, the researcher/ assistant will need to ask them some questions. If your child participates in our study, he or she will get to choose a reward (i.e., the gift certificate or movie pass described above).

**16. Signatures**

---

Subject's Name

The Principal or Co-Principal Investigator or representative has explained the nature and purpose of the above-described procedure and the benefits and risks that are involved in this research protocol.

---

Signature of Principal or Co-Principal                      Date

Investigator or representative obtaining consent

You have been informed of the above-described procedure with its possible benefits and risks and you have received a copy of this description. You have given permission for your participation in this study.

---

Signature of Subject or Representative                      Date

If you are not the subject, please print your name \_\_\_\_\_

and indicate one of the following:

- |       |                             |
|-------|-----------------------------|
| _____ | The subject's parent        |
| _____ | The subject's guardian      |
| _____ | A surrogate                 |
| _____ | A durable power of attorney |
| _____ | A proxy                     |
| _____ | Other, please explain:      |

---

Signature of Witness

Date

If a representative signs and if appropriate, the subject of this research should indicate assent by signing below.

---

Subject's signature

Date

APPENDIX E-INFORMED CONSENT FOR CONTROL PARTICIPANTS

**Children's Social Adjustment Study**

**BOX 100165; Health Science Center**

**University of Florida**

**Gainesville, FL 32608**

Dear Parent(s):

Your child is being asked to participate in a study which looks at how children get along with others, especially other children. We will be studying healthy children and children with cancer. The information we obtain may be useful in developing methods of helping children with cancer, who may have difficulties interacting with others. Your child will be asked to fill two questionnaires on this topic during one class session. The completion of these questionnaires will take roughly thirty minutes. Participation is voluntary and in no way will it effect your child's grades. Confidentiality will be maintained by assigning a number to you and your child and keeping materials in a

locked office in the Health Science Center. This project has been approved by the Institutional Review Board at the University of Florida ((352)-846-1494) and your child's school.

All children who participate in the study will have the choice of either a movie pass or a gift certificate to a fast food restaurant.

We also need you to complete the three attached questionnaires. Two of these forms looks at your child's social functioning and one asks you to provide personal information. Please sign at the bottom of this page indicating your consent for your child to participate in this study. We also ask that you print your child's name as well as circle which reward he or she would prefer. Please have your child return these forms to his/her teacher as soon as possible.

Thank you for your cooperation. If you have any questions, please feel free to contact us at 395-0680 ext. 5-4580.

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Wendy Kubar, M.S.

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Eileen Fennell, Ph.D.

Advanced Graduate Student

Professor

Clinical &amp; Health Psychology

Clinical &amp; Health Psychology

Parent Signature \_\_\_\_\_

Child's Printed Name \_\_\_\_\_

Reward Preference (please circle your child's choice):

movie pass

restaurant certificate

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